

# Pathways to care for AYA with cancer

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# Summary

- Service design
  - The problems and how service design might meet those
- The referral problem
- Potential solutions

# TYA have distinct clinical outcomes

- Over time & in many settings
- Differ from outcomes of people developing similar cancers at younger or older ages [1-5].
- TYA often have poorer survival than younger children with similar cancers [6, 7]
- Some poorer survival than older adults (and some better) [4, 7, 8]

1. Bleyer A et al., Oncologist. 2006;11(6):590-601
2. Ferrari A et al., Journal Adolescent Young Adult Oncology. 2013;2(3):112-7.
3. O'Hara C et al., Eur J Cancer. 2015. doi: 10.1016/j.ejca.2015.06.112
4. Stark D et al., Eur J Cancer. 2015 doi: 10.1016/j.ejca.2015.08.010.
5. Nicholson BD et al., Clin Oncol (R Coll Radiol). 2013;25(3):205-14.
6. Birch JM et al., Br J Cancer. 2008;99(5):830-5.
7. Trama A et al., Lancet Oncol. 2016; 17(7): 896-906
8. Lewis DR et al., Natl Cancer Inst Monogr. 2014(49):228-35

# AYA have specific distinct features

AYA with cancer are have specific medical needs;

- their presentations and symptoms are specific [1]
- biologically their cancer types and treatments are specific[2]
- they have distinct patterns of adverse effects [3-5]

AYA with cancer have specific supportive challenges;

- social - Balancing family, peers & individual[6].
- Personal - where is this young person in their developing biology from early childhood to mature adulthood? [7,8]

1. Dommett, R.M., et al. Br J Cancer, 2013. 108(11): p. 2329-33.
2. Tricoli, J.V., et al., Cancer, 2016. 122(7): p. 1017-28.
3. Rugbjerg, K., et al. J Natl Cancer Inst, 2014. 106(6): p. dju110.
4. Rugbjerg, K. and J.H. Olsen JAMA Oncol, 2015: p. 1-9.
5. Woodward, E., et al. Ann Oncol, 2011. 22(12): p. 2561-8.
6. Morgan, S., et al., J Clin Oncol, 2010. 28(32): p. 4825-30.
7. Viner, R.M., et al., J Epid ComHealth, 2015. 69(8): p. 719-20.
8. Bleyer, W.A., et al., Cancer, 1993. 71(7): p. 2413.
9. Barr, R.D. et al Cancer, 2006. 106(7): p. 1425-30.
10. Michelagnoli, M.P. et al , Eur J Cancer, 2003. 39(18): p. 2571-2.
11. Carr, R., et al., Clin Med, 2013. 13(3): p. 258-62.

# Problems with services

AYA cancer care cuts across distinct agencies;

- across site-specific clinical teams (e.g. breast cancer, sarcoma, lymphoma)
- across administrative boundaries in health care systems (e.g. haematology & oncology, adult & paediatric).
- i.e. interface group

Bleyer, W.A., et al., Cancer, 1993.  
71(7): p. 2413.

Barr, R.D. et al Cancer, 2006.  
106(7): p. 1425-30.

Michelagnoli, M.P. et al , Eur J  
Cancer, 2003. 39(18): p. 2571-2.  
Carr, R., et al., Clin Med, 2013.  
13(3): p. 258-62.

# What happens in the pathway route

Assume you know how patients with cancer generally present and obtain care

# Diagnostic Delays

- In 2012 UK patients data indicate delayed time to diagnosis for TYA patients
  - 57% > 3 GP visits before referral
  - 35% patients 2-8 months from hospital visit to diagnosis
  - Lymphomas, brain tumours and bone tumours the longest
- Comparing UK to Italy, France and other nations (Hungary, Denmark) in 2016 (Unpublished data)
- International cancer benchmarking project methods
  - 39% of patients reported visiting their GP twice or more before diagnosis.
  - 47% in England, 34% in Italy and 35% in the other countries combined
- Interesting to compare to younger children & older adults
  - It seems worse than either, but can't control for cancer type (yet)

# 'Too Young to Get Cancer?'

Understanding the challenge of achieving a timely diagnosis



Service Evaluation/Clinical Audit project to map the diagnostic pathway of 16-24yr olds referred to the South West TYA Service over an 18 month period.

## Aims

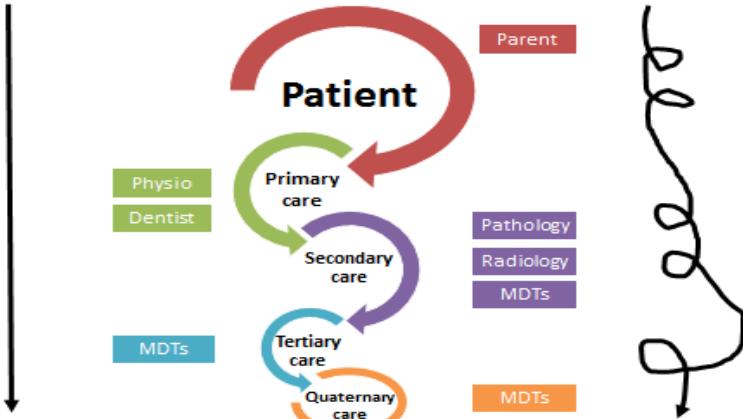
- Map the diagnostic pathway
- To better understand the referral pathways across the network
- Build evidence base
- Propose interventions?

## Methodology

- Patient permission (or their next of kin if deceased) to interrogate primary care and hospital records at source and extract information relating to details of all healthcare contacts (including date, contact type e.g. referral, consultation, reason and outcome)
- Bespoke database designed to capture data
- Route maps constructed and reviewed by clinical panel to identify key events, good practice, missed opportunities & potential interventions

# 'Too Young to Get Cancer?'

Every pathway is different



## Successes

- TYA response rate was high – 63%
- Support from all health care settings
- Inclusion of deceased patients
- Scope and depth of raw data collected at source



- TYA perceptions of their pathways vary and are important
- Debriefing exercises with TYA may have a positive impact on re-engagement with health care providers
- This study readjusts our understanding of where difficulties arise
- There should be as much focus in secondary care as primary care

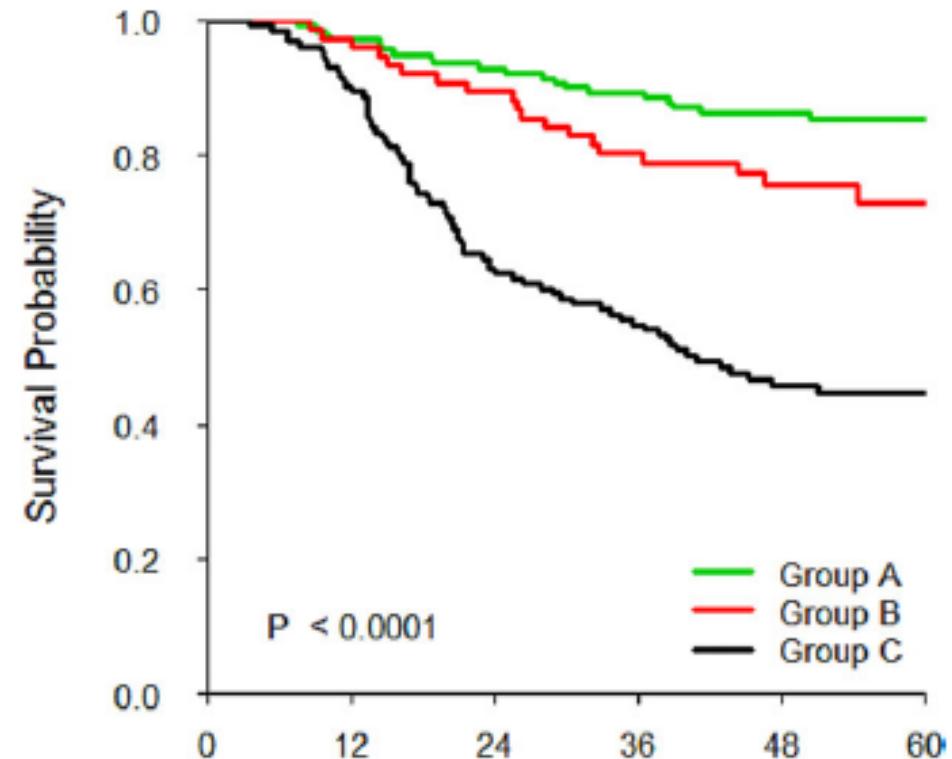
**Link to preliminary report:** <http://bit.ly/2ox9cfI>

# Stage of disease (late presentation)

- NSGCT of testis – Adolescents present with more disease than YA, but have similar outcomes [1]

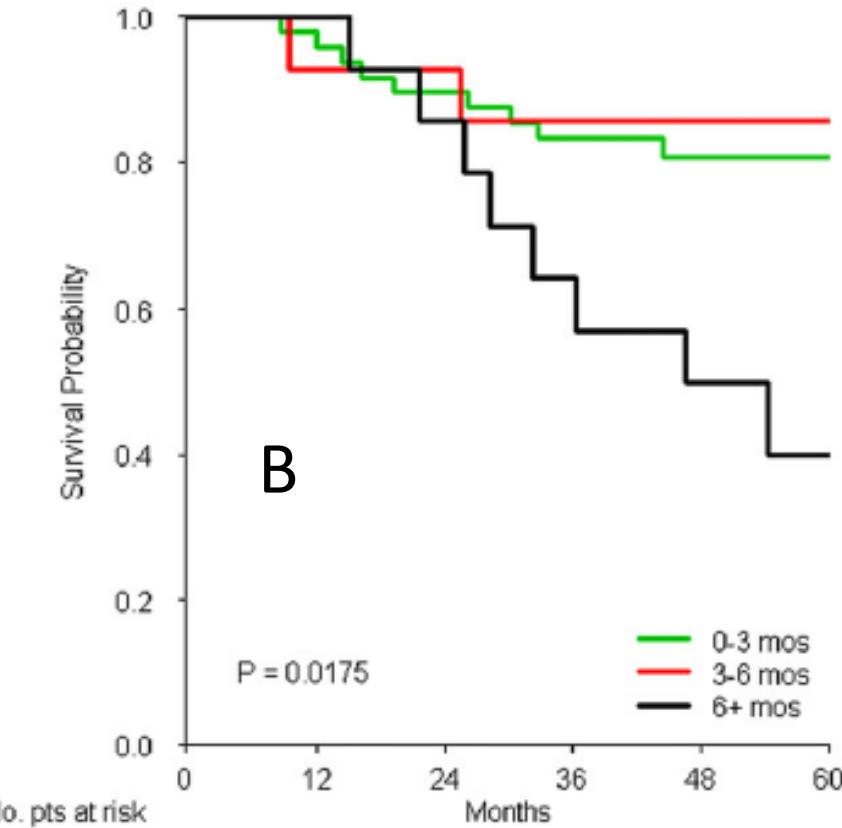
Not simple

- 351 Children and Adolescents referred to Milano [2]
- Empirical data-based cluster analysis of tumours seeking variation in the relation between time to diagnosis and OS
- 3 groups
- Group A- small tumours, many types, whatever TTD OS was high



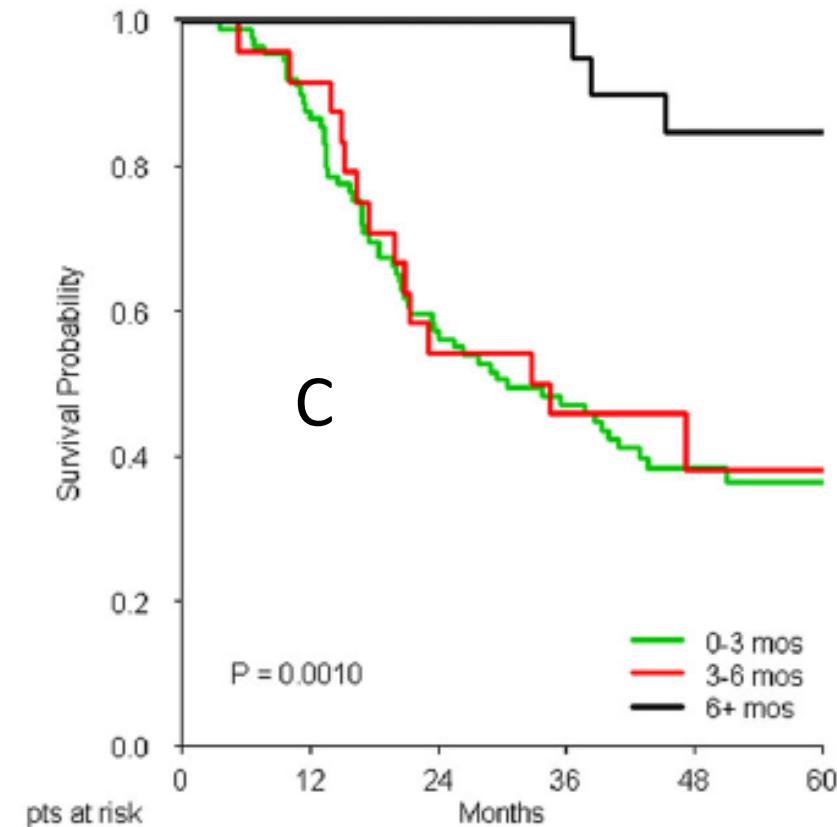
1. Amini A et al., J. Pediatr Urol. 2016 Aug 6. doi: 10.1016/j.jpurol.2016.06.014.
2. Ferrari et al., Pediatr Blood Cancer. 2016 Mar;63(3):479-85

# Locally/regionally advanced/metastatic disease



Non-rhabdomyosarcoma soft tissue sarcoma, and germ cell tumour

**Resistance develops with time before diagnosis e.g. bulk of disease?**



Brain tumours, rhabdomyosarcoma, osteosarcoma, and Ewing sarcoma

**Resistance doesn't develop over time - more indolent tumours with better outcomes?**

What can specialist AYA services add?

# Policy

# UK Teenage Cancer Trust Timeline

- **1989** Begin fundraising for the first Teenage Cancer Trust unit, to create a specialist centre of care for teenagers and young adults facing cancer
- **1990** The unit opens at the Middlesex Hospital, London
- **1994** First [International Conference on Teenage and Young Adult Cancer Medicine](#). Leeds, UK
- **1995** Teenage Cancer Trust's [education programme](#) begins to teach young students about cancer, its signs and treatments as well as giving healthy lifestyle tips.
- **2000** first show at [the Royal Albert Hall](#) called "The Who and Friends".
- **2001** first [Find Your Sense of Tumour weekend conference](#) for young people with cancer.
- **2004** first [skin cancer prevention campaign](#) is launched
- Establish [Teenagers and Young Adults with Cancer \(TYAC\)](#), a membership organisation for professionals involved in the care of young people with cancer
- World's first Professor of Teenage and Young Adult Cancer Medicine
- **2005** The National Institute for Clinical Excellence (NICE) publish the Children's and Young People's Improving Outcomes Guidance (CYPIOG) endorsing Teenage Cancer Trust's philosophy of care as best practice
- **2006** Teenage Cancer Trust helps establish the National Cancer Research Institute Teenage and Young Adult Clinical Studies Development Group
- Since then
  - 26 units across the UK, in each devolved nation
  - Last year they [raised £16 million to help young people facing cancer in the UK](#)



National Institute for  
Health and Clinical Excellence

Guidance on Cancer Services

## Improving Outcomes in Children and Young People with Cancer

The Manual



February 2006

Developed by the National Collaborating Centre for Cancer

**NICE** National Institute for  
Health and Care Excellence



## Cancer services for children and young people

Quality standard  
Published: 27 February 2014  
[nice.org.uk/guidance/qs55](http://nice.org.uk/guidance/qs55)

Hear about  
comparisons  
internationally in a  
later talk

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# NICE GUIDANCE 2005

## Key messages of the CYP IOG

All patients under 19 yrs old must be referred for definitive diagnosis and treatment in age appropriate facilities in the PTC

Young people between 19-24 should have unhindered access to age appropriate facilities and support when needed

“Age appropriate, safe and effective services as locally as possible, not local services as safely as possible”

# Choices

**where next?**

Cancer care choices for young people



Home Your choices Real stories Find a cancer hospital About cancer

If you're aged between 19 and 24 and have been diagnosed with cancer, you may have a choice about where to have your care. This website aims to guide you through some of the decisions you're likely to make.

Share    



**Real stories**

Watch videos of teenagers and young adults with cancer sharing their stories and experiences.



**Your choices**

Read about choosing where you would like to be treated and cared for, and use the choices checklist to think about what matters most when making your decisions.

 [Your choices checklist](#)



**Have you seen?**

CANCER RESEARCH UK  
CLIC Sargent Caring for Children with Cancer  
WE ARE MACMILLAN. CANCER SUPPORT

**About cancer**



Find out more about your type of cancer, and about the people

**Find a cancer hospital**



Search by postcode, location, hospital or cancer type to find a cancer care unit.

<http://www.nhs.uk/young-cancer-care/pages/index.aspx>

# Quality Statements 2014

- Statement 1. Young people (aged 16–24 years) with cancer have their diagnosis, treatment and support agreed and delivered by a cancer-site-specific multidisciplinary team and a teenage and young adult multidisciplinary team.
- Statement 2. Young people with cancer should be offered the opportunity to take part in clinical trials if they are eligible.
- Statement 3. Young people receiving chemotherapy have it prescribed using an electronic prescribing system.
- Statement 4. Young people with cancer, and their families and carers, have their psychological and social needs assessed at key points on their care pathway and receive support based on their identified needs.
- Statement 5. Young people who have had a central nervous system malignancy receive a specialist neuro-rehabilitation care package.
- Statement 6. Young people who have been treated for cancer have an end-of-treatment summary and care plan that includes agreed follow-up and monitoring arrangements.
- Statement 7. Young people with cancer are assessed for potential future fertility problems and advised about their options for fertility preservation before treatment is started.

# Co-operation

# Co-operation

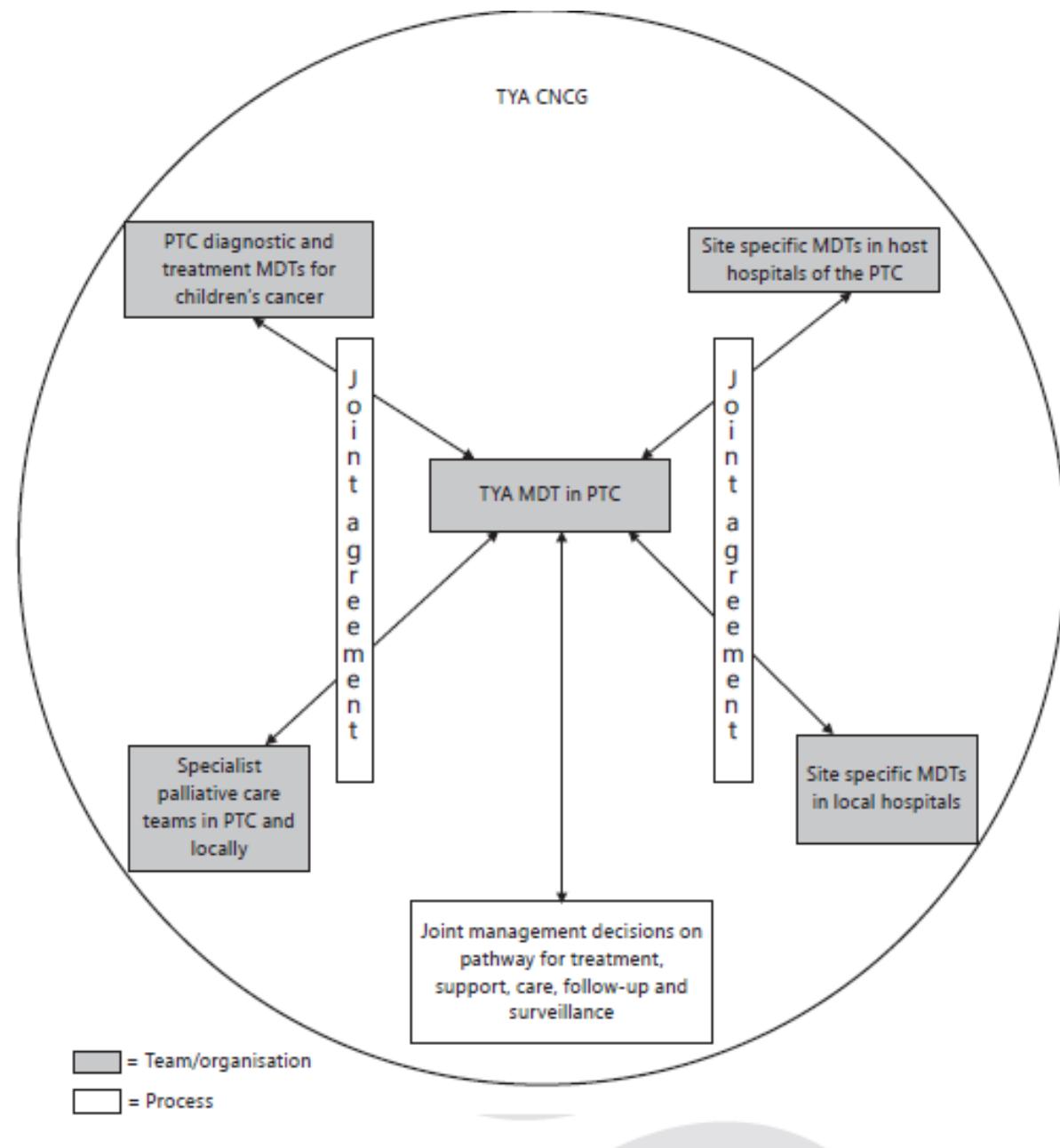
	Don't work together	Work together informally	Work together formally	Don't know
Paed-TYA	4	21	65	16
TYA-Adult	9	30	41	25
Paed-Adult	18	46	29	10
Onc-Haem	7	29	60	10
Primary-Second	15	32	41	16
Primary-Palliative	13	27	48	15
Second-Palliative	5	25	51	22

Professionals survey 2014 – 22  
nations, >200 patients, > 22  
clinical professional areas

90% wanted  
national guidance

# Policy

- All newly diagnosed TYA must have their care discussed at a single regional TYA multidisciplinary team meeting
  - Diagnosis
  - Plan
  - Trials
  - Fertility
  - Supportive care
  - Choice of place of care



# TYA MDT work together

- Inaugural Meeting 28-01-08 - weekly since
- All young people aged 13-24 discussed, diagnosis, oncological and supportive care
- To develop
  - Mutual trust
  - Referral pathways



# Now

- Non-designated hospitals within the English NHS are not commissioned to provide treatment for cancer in AYA. Therefore if they provide treatment, they are not paid for that.
- Professionals including clinical and managerial groups across a region meet as a network and share their service enhancement and development
- Older AYA aged 19-24 must be offered an informed choice of whether to go to the principal centre or chose care in a designated hospital, allowing them to trade off the risks and benefits.
- Defining how to explain that choice has been subject to a specialist national project but it remains unknown how this is done in practice.

# Education and Training

# Skills- in the view of professionals

## Relevant to pathways to care

A scoping exercise of favourable characteristics of professionals working in teenage and young adult cancer care: 'thinking outside of the box'

GIBSON F., FERN L., WHELAN J., PEARCE S., LEWIS I.J., HOBIN D. & TAYLOR R.M. (2012) *European Journal of Cancer Care* **21**, 330–339

### Box 1. Top key competencies for health professionals working in TYA cancer care

- 1 Expertise in treating paediatric and adult cancers.
- 2 Understanding cancer.
- 3 [Delivery of] appropriate information about the disease.
- 4 Bridge between TYA need for information and parental reaction to withholding information.
- 5 Giving mutual respect.
- 6 Good knowledge and skills about diagnosis.
- 7 Using team skills.
- 8 Having time to sit and talk/spend time with young people.
- 9 Helping young people express their emotions.
- 10 Involvement of siblings.
- 11 Not patronising.
- 12 Respect privacy.
- 13 Take the young person seriously.

# Comparing some written medical curriculae

		ESMO/ASCO	SIOPE	ESMO/SIOP-E on-line module	UK College physicians	UK College paediatrics
Health and epidemiology	Experts in cancer, diagnosis, treatment	Yes	Yes	Yes	Yes	Yes
TYA behaviour	Personal development	Yes	Yes	No	Yes	Yes
	Take time show respect - individuality & privacy	?	Yes	No	Yes	Yes
	Understand emotions	Yes	Yes	Yes	Yes	Yes
	Understand family context	No	Yes	Yes	Yes	Yes
Professional behaviour	Information giving	Yes	Yes	Yes	Yes	Yes
	Trials	Yes	No	Yes	Yes	Yes
	Self-management & transition	No	No	No	No	Yes
	Team player	Yes	Yes	Yes	Yes	Yes
Leadership	Advocacy	No	No	No	No	No
	Service development	No	No	No	No	Yes

Note there are others...

# Similarities and Differences

## Similarities

- Diseases, health, epidemiology
  - Late effects including Fertility
- Psychosocial elements
- MDT-working
- Trial design and recruitment

## Differences

- Specific professional behaviours-  
e.g. Leadership
- Nature of services
  - Specialisation, Joint Paediatric-Adult working, Transition
- Detail
  - Pharmacology, Registries, End-of Life, patient behaviours
- Mechanisms to teach and assess
  - Specific, systematic

# Canada

Abha Gupta

- Area of Focused Competence (AFC)
- Applicant
  - Royal College Hematology, Medical Oncology, Pediatric Hematology/Oncology, Radiation Oncology
  - or enrolment in a **Royal College accredited** residency program
- Upon completion of training
  - function as an **enhanced practice specialist** in AYA Oncology
    - Medical skills
    - Communicator & **Collaborator & Manager**
    - Advocate – individual & community
    - Scholar & Professional

Item	Number
AYA Oncology Logbook	1
Consultation notes/clinical summaries/discharge summaries/follow up notes	18
Referral notes/consultation requests	5
Survivorship care plan	1
AYA Oncology Care Path	2
Multi source feedback	2
Patient evaluation tool	1
Mini CEX	1
Transfer letter	1
Attestation of participation in a committee	1
Reflective critique/analysis	1
Scholarly project	2
Scholarly presentation	1
Log of teaching activities	1
Total	38

**3rd Global Adolescent & Young Adult Cancer Congress**

December 4<sup>th</sup> - 6<sup>th</sup> 2018  
Sydney | Australia

**Abstract submissions now open**

Submit now

**Adolescent and Young Adult Cancer GLOBAL ACCORD**

**YOUTH CANCER SERVICE** | **canteen**

19.10.2018 (1)

Hall B3 - Room 22

14:00

14:00 - 15:30      1h 30m  
ESMO-SIOPe: Multidisciplinary management of life-after-cancer issues in adolescent and young adult survivors: Medicine and beyond (ID 231)

15:00

Hall B3 - Room 22  Special session

**ESMO-SIOPe: Multidisciplinary management of life-after-cancer issues in adolescent and young adult survivors: Medicine and beyond (ID 231)**

Date 19.10.2018

Time 14:00 - 15:30

Location Hall B3 - Room 22

Moderators Giannis Mountzios (Athens, GR), Daniel Stark (Leeds, GB)

Special session

**Introduction (ID 564)**

Lecture Time 14:00 - 14:05

Speakers Daniel Stark (Leeds, GB)

Special session

**Fertility preservation, parenthood and sexual health in AYA cancer survivors (ID 565)**

Lecture Time 14:05 - 14:25

Speakers Fedro A. Peccatori (Milan, IT)

Special session

**Late cardiovascular toxicity of anti-cancer treatment in adolescents and young adults (ID 566)**

Lecture Time 14:25 - 14:45

Speakers Kathrine Rugbjerg (Copenhagen, DK)

**Going back to school or work after cancer diagnosis: Professional and social re-integration of AYA cancer survivors (ID 568)**

Lecture Time 14:45 - 15:05

Speakers Pia R. Riis Olsen (Aarhus, DK)

Special session

**Psychosocial, nutritional and physical activity aspects of AYA cancer survivors (ID 567)**

Lecture Time 15:05 - 15:25

Speakers Alexander Stein (Hamburg, DE)

Special session

**Conclusions (ID 570)**

Lecture Time 15:25 - 15:30

Speakers Giannis Mountzios (Athens, GR)

**MUNICH 2018 ESMO congress**

**MUNICH GERMANY 19-23 OCTOBER 2018**

**Save the date!**

Pathways after the cancer  
treatment

# Develop transition

- Young people treated for their cancer in children's services, who are no longer children
  - Big challenge
    - 1200 prevalent patients in Leeds
    - Some high risk for new disease
    - Screen-detection feasible for many (endocrine, cardiac, diabetes)
  - Who cares for them and where?
    - Needs-dependent (late effects, risk groups)
    - Relationships with professionals & preferences to change place of care are complex
    - Service designs are very different
      - Role of peers, family
      - Expectations of the patient personally

# Transition NOT Transfer

## **trans·fer**

- to convey or remove from one place, person, etc., to another: ‘He transferred the package from one hand to the other.’
- to cause to pass from one person to another, as thought, qualities, or power; transmit
- to remove oneself from one place to another: to transfer from the New York office to London
- to be moved from one place to another: to transfer to



## **tran·si·tion**

- movement, passage, or change from one position, state, stage, subject, concept, etc., to another; change: the transition from adolescence to adulthood

# Ongoing care, monitoring and late effects

- Cardiovascular disease
  - Population-based follow-up of more than 40,000 1-year survivors of adolescent and young adult cancer
    - one of four admitted to the hospital for cardiovascular disease
    - 30% higher rate than the general population
  - The risk was substantially elevated in all ages up to 70 years
    - The absolute excess risk for survivors aged 20 to 59 years was ~400 new cases of cardiovascular disease per 100,000 person-years
      - overall cumulative risks of 45% at age 60 years and 52% at age 70 years.
- The cardiotoxic effects of cancer treatment, the underlying cancer, and/or lifestyle factors peculiar to survivors of AYA cancer manifest themselves many decades after initial diagnosis.

# Summary

- Pathways to care are variable
- Some patients have very long delays to diagnosis and treatment
- This can influence the outcome but not always
  - in some cancer types more than others
- Team working is one way to try to overcome that
- Education and training is another – you are now the champions of that.
- Pathways to care don't stop at the end of treating the cancer
  - Late effects care
  - Transitional care