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Deirdre Brunton– Teenage Cancer Trust, TYA
Lead Nurse

Developing Services for Teenagers and Young Adults (TYA) with Cancer
• NICE IOG Published August 2005

• Instigate and motivate -SW Specialised Commissioning Group- Teenage Cancer Trust funded TYA Program Manager
South West
Implementation Strategy
What happened to get us here? (1)

- UBHFT Conference and SW SCG stakeholder event > UBHFT Cancer Board 25th July 2008 > confirmation of TYA PTC status

- Final TYA Implementation Summary submitted to nCAT > model of PTC and up to 8 shared care centres

- TCT TYA Lead Nurse appointed at PTC 2009

- TYA MDT co-ordinator identified at PTC

- Identification of resources agreed by commissioners 2009/2010:
  - recurring funding for up to 4 wte nurse posts
  - p/t TYA psychological support post
What happened to get us here? (2)

- Development of Shared Care and designation requirements > self assessment proforma

- SW wide approach to On Line TYA MDaT > Non-medical research proposal > links with Shared Care Units (SWSCG / external funded) ISEEU Private Industry Partnership

- Appointment of TYA Lead Clinician at PTC (external funded)

- SW wide approach to patient choice/support/engagement > ‘realshare’ website- Teenage Cancer Trust Research > link to NHS Choices

- SW wide stakeholder engagement events x 2
South West TYA Cancer Services

KEY
- Principle Treatment Centre
- Shared Care Centre

Release: Jan-11
What happened to get us here? (3)

- TYA peer review measures – gap analysis Sept 11 > link to designation work programmes
- Mainstreaming TYA services > links to future work and other programmes
- Recruitment of Clinical Liaison posts (one outstanding at Sept 11)
- Designation process for PTC and Shared Care units inc. visits Jan 2011 > quarterly feedback to SCG
- Link with SCSCG / Southampton Hospital / Dorset Cancer Network > designation process

No of patients by age and hospital of diagnosis  2001 - 2005

<table>
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<th>Age</th>
<th>Cheltenham</th>
<th>Gloucester</th>
<th>Exeter</th>
<th>Torbay</th>
<th>Plymouth</th>
<th>Barnsatple</th>
<th>Truro</th>
<th>Bristol</th>
<th>Taunton</th>
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<td>71</td>
<td>46</td>
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Three Counties (13%)
Peninsula (36%)
ASW (51%)
Developing a TYA Service & Shared Care Approach for Young People whilst awaiting a Teenage Cancer Trust Unit/s
PTC Priorities

- Transition
- Survivorship
- User Involvement Development
- Recruitment for clinical trials
- Palliative care provision
- Research/Education of Staff/empowerment/profile/cultural change
- Psychological and social support
- Vocational issues for patients
Using a Web Based Communications Platform TYA MDaT And Co creating an online Social Network

TYA Patients in the South West Region
Standard Approach South West

TYA Care
South West NHS
Teenagers and Young Adults with Cancer Service
Transition

‘Transition is a lengthy process and should continue into adult care’ RCPCH 2003

‘Transition should be a guided, educational and therapeutic process rather than an administrative event’ NSF 2004

The process begins in childhood, escalates in the teenage years and continues into adulthood...and is ever evolving...

.....we’re not talking about transfer
TYA Clinical Liaison Nurse

• Professional linchpin to deliver a TYA Service for young people in PTC and across all Shared Care designated in the South west

• Identify, processes and pathways of care for TYA with cancer care with PTC

• Identify all patients between the ages of 15-25 newly diagnosed with cancer in their area

• Support and act as a Key Worker for patients who do not already have a key worker
TYA Clinical Liaison Nurse

- Develop strong professional links with the TYA Team in their area i.e. make professional links with Consultants, Clinical Nurse Specialists and all staff exposed to the care of Teenagers and young adults with cancer.

- Develop their links with their Cancer Network and their User Involvement

- Facilitator/ Educator

- Moderator ‘Realshare’ Website.
TYA MDaT

To discuss all new patients plus existing patients who have relapsed or have “issues” (clinical or psychosocial)

- Specific aims of MDaT:

  Undertake a developmental focused holistic assessment:

  1) To ensure statutory cancer registration is completed
  2) To provide clinician/professional peer support, review diagnosis and treatment, promote Clinical Trial access, fertility advice/expertise, educational/vocational support, financial advice support and ongoing review
  3) To deliver psycho-social support based on the unique developmental holistic assessment of each patient
New Diagnosis / Already on treatment

How will the system work
- IM & T
- People

Register
- What
- Where

Systematic Review
- What

MDaT review Discussion

Log & Register
- TYA Registration National
- SCR MDaT meeting
- Schedule Review

SSG Requesting Advice
- Re TYA

Report Recommendations

Stop & Think

Questions

Process Flow

Request

TYA: MDaT Central Line
Version 1.01 April 20th 2009
TYA MDaT: An MDT in Development

- Running weekly since October 2009

- Currently taking referrals from Bristol and SW Shared care

- Ultimately will be mandatory

- On-line platform overcomes the logistical geographical issues
TYA CENTRE: PATIENT NOTIFICATION
(fore ages 15 to 24 years)

Surname/family name: BLOGGS
Forenames: JOE

Diagnosis: HODGKIN'S LYMPHOMA
Nature of specimen: Slides for opinion x 13 Their no H09/54602) Blocks for Opinion x 1 their no H09/5465-a1

Request: 09-1414466-1304/09 11:38
Specimen number: BC09-455

NOTES

MDaT Online Discussion
TYA MDaT Platform

Sharing PACS with attendees

Platform in process

Return to platform
Service

ISEEU™ Global Courier

Securely send and track important files of any size and type
The speedier and safer way to distribute your sensitive data

Username: [Input]
Password: [Input]

Log in

Important Information

Do not attempt to log-in unless you are an authorised user. The data on this system is PRIVATE PROPERTY.

Access to this data is only available for authorised users for authorised purposes. Unauthorised access contraves the Computer Misuse Act (1990) and may incur criminal penalties as well as damages. Proceed only if you are an authorised user.
Information seeking

- AYA with cancer indicate that they prefer to visit cancer websites that contain cancer-related information, provide the ability to chat with AYA with cancer, and offer some type of game.

Challenges and opportunities

- Cross boundary working
- Approach to care across disease site specific teams
- Access to age appropriate facilities
- Establishing TYA shared care
- Developing TYA specific survivorship programmes
- Planned transition between children and young people’s services and between young people’s and adult services.
- Improvement in outcomes and experience for TYA
- Model of care for other groups?
Opportunity to
- Identify life-stage psychosocial issues and provide appropriate support during and after treatment
- Engage with Survivorship strategies
- Focused research on reducing treatment toxicity and identifying needs & acting on results

Teenage young adult cancer service- spring board to change
Thank you and any questions?