ANNUAL REPORT FROM THE TEENAGE AND YOUNG ADULT SOUTH WEST CANCER SERVICE

January – December 2016

Version: v1.2
Date: July 2017

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SUMMARY

1.1 Key Achievements

- Continued capital and revenue support from, and close collaboration with, Teenage Cancer Trust to further develop resources both at the Principal Treatment Centre and at designated hospitals within the TYA (Teenage & Young Adult) SW (South West) network.

- In line with the service objectives for 2015 the service has consolidated and maintained the networked model of care. This has been supplemented and supported through the appointment of a Regional TYA Service Coordinator funded by Teenage Cancer Trust, in an addition to the bid to increase the TYA Specialist Nurse workforce.

- Ongoing development of the TYA Wellbeing initiative role resulting in a number of successful projects such as Teenage Cancer Trust funded 'The Way Forward' programme and a reflexology service.

- The regional service has actively promoted peer and social activities for young people both at the PTC and equally in each of the designated hospitals. Such regular engagement with young people in a programme of activities built around social events promotes and fosters peer support.

- The TYA IAM (Integrated Assessment Map) Portal Project is reaching final evaluation in the TYA SW cancer service network and has been piloted with colleagues in the East Midlands TYA service this year. Following the successful pilot of the IAM Portal, the project is being taken forward and at a national by Teenage Cancer Trust, in partnership with Macmillan Cancer Support, Sitekit and University Hospitals NHS Foundation Trust.

- 'Too Young to Get Cancer?', a project mapping the pathways to diagnosis in TYA with cancer and the only children's and young person's project supported by the national ACE (Accelerate, Coordinate & Evaluate) programme, was completed in November 2016. The diagnostic pathways of 104 young people from across the region were mapped and dissemination of findings continues.

1.2 Key Challenges

- Managing the network - our geography and our service philosophy mean we have to continue to think imaginatively about what we do and how we influence the delivery of care across the network.

- TYA pathways – there are various pathways for TYA patients across the region dependant on age and treatment location. In order to ensure shared engagement in the development of pathways, service standards, and quality and development initiatives in 2017 we will be undertaking a piece of work to clarify pathways and guidelines.

- Clinical trials - there is a specific concern about the availability of, and access to clinical trials for TYA patients. The recently published ‘Achieving World Class Cancer Outcomes’ report includes a specific target for recruitment of 50% of TYA to clinical trials by 2025.

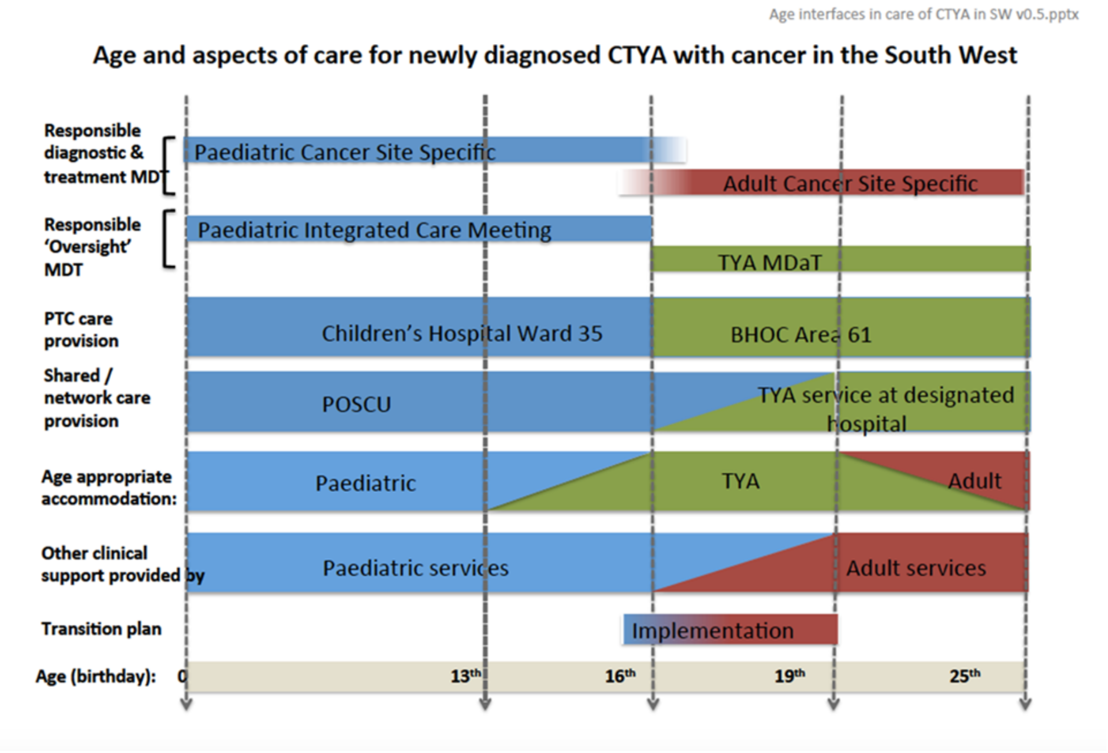
- Lack of clarity over commissioning arrangements for the whole pathways of care and the current financial climate, both in the NHS and third sector, are impacting service development initiatives. This specifically relates to ongoing funding of posts.

2. SERVICE DESCRIPTION

2.1 Population served

University Hospitals Bristol NHS Foundation Trust (working in partnership with North Bristol NHS Trust) has been the designated Principal Treatment Centre (PTC) for Teenagers and Young Adults (TYA) with cancer in the South West (SW) of England, a population of almost 5 million, since 2011. The PTC oversees the delivery of specialist malignant haematology and oncology care along with the provision of emotional, social and practical support to young people diagnosed with cancer. During 2016, a review of the lower age threshold for referral to the TYA service was conducted in collaboration with the childhood cancer service. This considered the complexity of the age interface in relation to: MDT discussion; provision of in-patient care at the PTC; provision of paediatric shared care and TYA designation across the region; the availability of age appropriate accommodation; and the provision of support from either paediatric or adult services. Variability exists in the policies about the upper age limits for paediatric care across hospitals involved in the network. This is illustrated in figure 1.

Figure 1. Age & aspects of care for newly diagnosed CTYA in the South West



Consequently the lower age threshold for referral to the TYA service was raised to 16 years (i.e. all involving young people diagnosed on or after the 16th birthday). The upper age threshold will not change (i.e. diagnosis before 25th birthday).

The implications of this decision for the service has been that

- all young people newly diagnosed with cancer from the 16th birthday to before the 25th birthday must be referred to the TYA Multi-Disciplinary advisory Team (MDaT) whether or not they are under paediatric or adult site specific cancer care.

- all children and young people newly diagnosed with cancer before the 16th birthday should be referred to the paediatric oncology/haematology service.
- young people newly diagnosed with cancer from the 16th birthday and before 18th birthday may be referred either to paediatric or adult cancer services. Referral to paediatric services at this age may still be appropriate in relation to the nature of the diagnosis, the preference of the young person and his/her family; and his/her developmental status. Before making this decision, however, due consideration should be given to how shared care can be delivered, the need for a transition plan, and the possibility of requiring subsequent transfer to adult services.
- young people newly diagnosed with cancer from the 18th birthday should be referred to adult site specific cancer services.
- all children and young people who were originally diagnosed with cancer prior to the 16th birthday but who transit their 16th birthday whilst still on treatment, should be referred to the TYA MDaT whether or not they remain under paediatric care.

The purpose of this policy is to ensure that young people entering the TYA age range whilst already on treatment have the opportunity to receive support from the TYA service, and undergo a discussion to facilitate transition and the possible future transfer to adult cancer services.

2.2 Background to the service and its model of care

The NHS England Standard Contract for TYA with cancer (B17/S/a) reflects previously published national guidance (NICE IOG 2005) and states that young people aged 16-18 years (i.e. to 19th birthday) should be referred to a TYA PTC for treatment in age appropriate facilities and that young adults aged between 19 and 24 (i.e. before 25th birthday) should be offered the opportunity to receive treatment at a PTC in age appropriate facilities. However, when the TYA service was first commissioned in the SW, a devolved network model of care was agreed with the Specialised Commissioners.

For geographical reasons, and in line with a long standing and well-established regional 'shared care' network established in paediatric oncology in the same region, it was agreed that a regional network for TYA care would be established linking the PTC in Bristol with 6 designated hospitals (Gloucester, Bath, Taunton, Exeter, Plymouth and Truro) offering TYA services across the SW. The rationale for this decision was to ensure that all young people were able, whenever possible and appropriate, to access treatment locally. The TYA SW network has since been supported by UH Bristol, the Specialist Commissioners, the Teenage Cancer Trust, and others, to develop this approach (see section 2.4).

In order to support this arrangement, all patients were offered access to a dedicated TYA Nurse Specialist (NHS funded and subsequently adopted by Teenage Cancer Trust) and by a TYA Lead Clinician in each of the designated hospitals.

2.3 Facilities

There are two areas for the care of young people with cancer in the Principal Treatment Centre at UH Bristol: Ward 35, in the Bristol Royal Hospital for Children, and Area 61, a newly built TYA Unit for young people in the Bristol Haematology and Oncology Centre (BHOC).

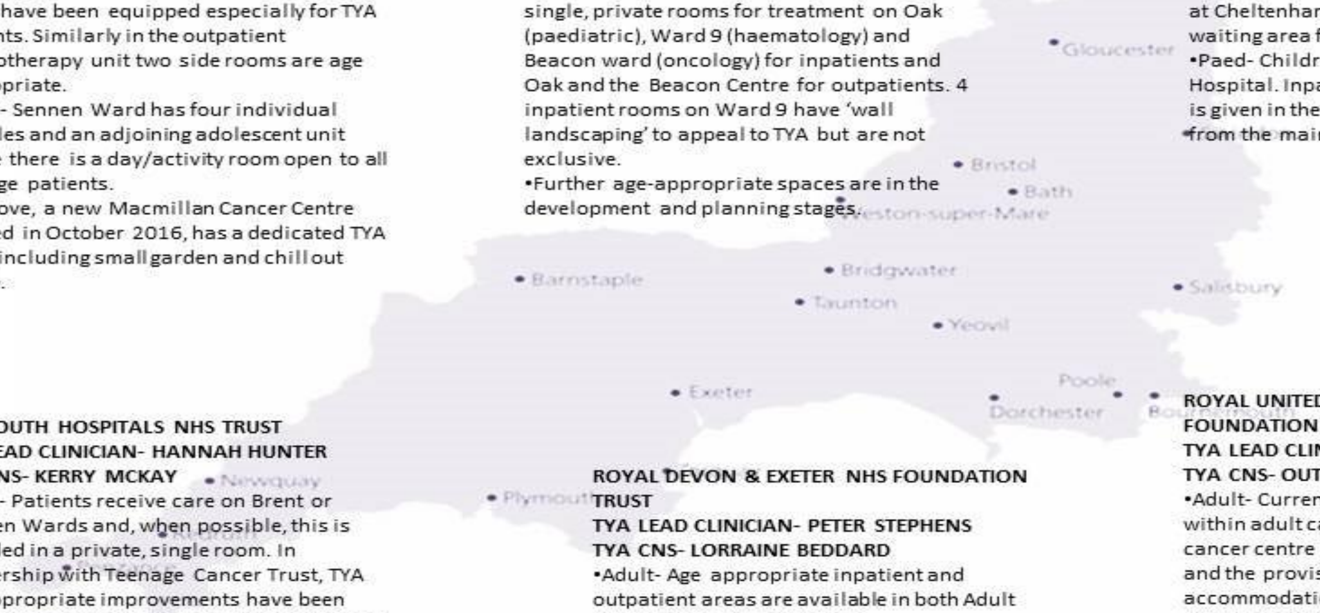
Ward 35, redeveloped in December 2012 for the care of young people aged 11-16, is a 14-bedded ward consisting of ten single en-suite bedrooms and a four-bedded bay. Four beds in Ward 35 directly support young people with cancer. There is active collaboration between Ward 35 and Area 61.

Area 61 was funded and developed in partnership with the Teenage Cancer Trust. The Unit opened in 2014 and provides care, treatment and consultation for young people with cancer aged from 16 to 24. It is built over two floors with one floor dedicated to in-patients featuring five en-suite rooms; a social area equipped with gaming and entertainment equipment and a kitchen and dining space; quiet room; treatment room; and a more recently planned wellbeing room . The other floor is for day patients featuring three treatment ‘pods’; three consulting rooms; a procedure room; social space; waiting area and a staff office.

Age specific facilities have been/are being established in many of the designated network hospitals, with Teenage Cancer Trust support. These developments are also summarised in Figure 2.

Figure 2. Age specific facilities at TYA designated hospitals

Age appropriate facilities across the TYA SW network



ROYAL CORNWALL HOSPITALS NHS TRUST
TYA LEAD CLINICIAN- TOBY TALBOT
TYA CNS- HANNAH HEAYN

•Adult- On the Adult Haematology and Oncology ward two side rooms and a quiet room have been equipped especially for TYA patients. Similarly in the outpatient chemotherapy unit two side rooms are age appropriate.

•Paed- Sennen Ward has four individual cubicles and an adjoining adolescent unit where there is a day/activity room open to all teenage patients.

The Cove, a new Macmillan Cancer Centre opened in October 2016, has a dedicated TYA area, including small garden and chill out space.

PLYMOUTH HOSPITALS NHS TRUST
TYA LEAD CLINICIAN- HANNAH HUNTER
TYA CNS- KERRY MCKAY

•Adult- Patients receive care on Brent or Bracken Wards and, when possible, this is provided in a private, single room. In partnership with Teenage Cancer Trust, TYA age appropriate improvements have been implemented in both in and outpatient areas

•Paed- Patients receive care in the Children's & Young People's Outpatient Department (CYPOD) or on Wildgoose Ward.

TAUNTON & SOMERSET NHS FOUNDATION TRUST
TYA LEAD CLINICIAN- BELINDA AUSTIN
TYA CNS- LORRAINE BEDDARD

•Adult and Paed- TYA patients are offered single, private rooms for treatment on Oak (paediatric), Ward 9 (haematology) and Beacon ward (oncology) for inpatients and Oak and the Beacon Centre for outpatients. 4 inpatient rooms on Ward 9 have 'wall landscaping' to appeal to TYA but are not exclusive.

•Further age-appropriate spaces are in the development and planning stages.

ROYAL DEVON & EXETER NHS FOUNDATION TRUST
TYA LEAD CLINICIAN- PETER STEPHENS
TYA CNS- LORRAINE BEDDARD

•Adult- Age appropriate inpatient and outpatient areas are available in both Adult Oncology and Haematology.

•Paed- Two designated TYA inpatient rooms are available on Bramble ward in the Paediatric unit.

GLOUCESTERSHIRE NHS FOUNDATION NHS TRUST
TYA LEAD CLINICIAN- ASHA JONNY
TYA CNS- MEG WILSHER

•Adult- The Gloucestershire Oncology Centre at Cheltenham General Hospital. Specific waiting area for TYA.

•Paed- Children's Centre at Gloucester Royal Hospital. Inpatient and outpatient treatment is given in the dedicated oncology unit, away from the main children's ward.

ROYAL UNITED HOSPITALS BATH NHS FOUNDATION TRUST
TYA LEAD CLINICIAN- SALLY MOORE
TYA CNS- OUTREACH FROM UHBRISTOL

•Adult- Currently no age appropriate facilities within adult cancer service facilities. A new cancer centre is proposed (opening 2019-20) and the provision of TYA age appropriate accommodation is under discussion.

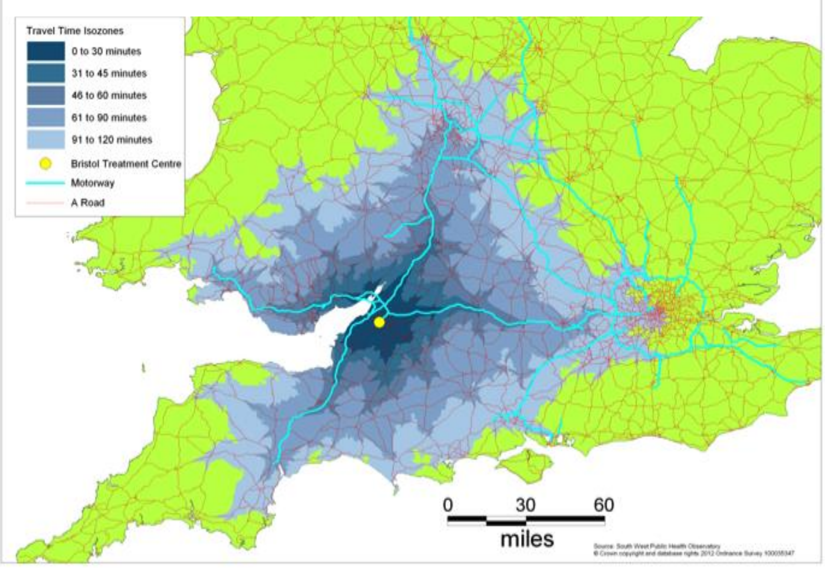
•Paed- Paediatric oncology shared care team in collaboration with the Paediatric PTC team offer two private en-suite rooms with adjacent sitting room for TYA use.

AGE THRESHOLDS FOR ACCESS TO PAEDIATRIC AND ADULT SERVICES VARY ACROSS THE NETWORK

2.4 The Network Model of Care

In the past, the development of TYA cancer services in the UK has benefitted from a model of centralised care that supported the development of clinical expertise and the provision of age appropriate accommodation. From the outset, this was not considered the optimal model for the SW, partly because of the geographical characteristics of the region, with long travel times for many patients to the PTC in Bristol (Figure 3) and partly because it was felt that it should be possible to deliver high quality care for many young people using the resources and skills available at the designated hospitals, closer to their home, with the support of the principal treatment centre (PTC). In order to achieve this, the specialised commissioners invested in a number of TYA specialist nurse posts linked both to the PTC and to the designated hospitals.

Travel times to TYA Principal Treatment Centre in Bristol



Source: South West Public Health Observatory
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Figure 3. This illustrates the challenge for delivering centralised care in the SW, particularly for patients in Devon & Cornwall, many of whom reside > 2hours travel time away from Bristol. (The green areas indicate one way travel times >120 minutes)

The network approach aligns with one of the other key statements in the NICE IOG (2005), which states: *"Equitable access to services is a key issue. Many services have evolved over time and within geographical and other constraints, such as the availability of expertise and level of funding. These constraints remain real, but efforts must be made to minimise the variations in access. The overriding principle for the provision of services must be safe and effective services as locally as possible, not local services as safely as possible"*.

The network model of care adopted for TYA patients in the SW seeks to address the key principles set out in the Blueprint of Care (Teenage Cancer Trust & TYAC, 2016) and is in line with the vision for the future of the health service in England as articulated in the NHS England Five Year Forward View (October 2014). The approach is further supported by the findings of the recently evaluated Teenage Cancer Trust Northwest (NW) Pilot project which introduced a range of specialist staff to support young people wherever they were treated, both at hospital and at home. The positive experience of the NW pilot mirrors the benefits identified in the SW through the improvement of patient pathways and the enhancement of the patient experience by ensuring that both age-appropriate support and site specific expertise are offered at the earliest point.

2.5 The role of the TYA Multi-Disciplinary advisory Team (MDaT)

Cancer registration data suggest that approximately 160-180 TYA patients are diagnosed each year across the SW. In order to best support and coordinate its network responsibilities, the TYA SW team has developed the requirement for a TYA MDT (NICE IOG, 2005 and Manual for Cancer Services: Teenage and Young Adults Measures, April 2014) as a weekly online, WebEx based meeting which allows patients from across the region to be discussed between the TYA team at the PTC and local clinicians at the designated network care hospitals.

The MDaT now also links with the development of the TYA IAM Portal (see section 10.1) so that young people can assess their needs and gain targeted support and information. Patients are encouraged to transmit their assessment of their needs to the professionals caring for them, thus forming the structure around which the discussions that take place at the TYA MDaT are framed. The data generated from the IAM, and from the discussions at MDaT, can be captured within the IAM Portal system to provide information about how the service is meeting needs and where gaps exist. This work derived directly from an early initiative by the TYA SW clinical service and was further developed through the resource of the Macmillan funded On Target programme.

3. STAFFING

Staffing for the TYA SW service consists of those who work at the Principal Treatment Centre (PTC) in Bristol and those who work at the six designated TYA hospitals across the region.

3.1 At the Principal Treatment Centre

Staff at the PTC represent both those in the core TYA team and those who have a key role in supporting the TYA MDaT (as defined in Peer Review Measures). Details are shown in Table 1, below.

Table 1: Details of staff with TYA responsibilities at the PTC

Role	Post holder at 31.12.16	Full/Part time (wte)	Funded by
TYA Core Team			
Lead Clinician	Dr Rachel Dommett[1]	1.0wte (0.2wte specific to TYA)	NHS
Teenage Cancer Trust TYA Lead	Jamie Cargill	Band 8a 1.0wte	Teenage Cancer Trust

Nurse			
Clinical Psychologist	Dr Laura Baker[2]	Band 8a 1.0wte (0.2 wte TYA)	NHS
Social Worker	Suzie Holmes		CLIC Sargent
TYA Specialist Nurse	Jax Hulbert	Band 7 1.0wte	NHS
TYA Specialist Nurse	Claire Lewis-Norman[3]	Band 7 1.0wte	Teenage Cancer Trust
Youth Support Coordinator	Hannah Lind	Band 5 1.0wte	Teenage Cancer Trust
Wellbeing Coordinator	Fran Hardman[4]	Band 7 1.0wte	Macmillan Cancer Care
Regional TYA Service Coordinator and Project Manager	Hannah Pring[5]	Band 5 1.0wte	Teenage Cancer Trust
MDaT coordinator	Becky Mathias	Band 4 1.0wte (0.5wte TYA)	NHS
Clinicians with designated responsibilities to the TYA service			
Adult Haematology[6]	Dr Caroline Furness	0.5 PA	NHS
Adult Sarcoma[7]	Dr Adam Dangoor	0.5 PA	NHS
Adult CNS[7]	Dr Jilly McLean	0.5 PA	NHS
Adult Germ Cell[7]	Dr Anna Kuchel	0.5 PA	NHS
Paediatric Oncology[7]	Dr Anthony NG	0.5 PA	NHS
Palliative Care[8]	Dr Rachel McCoubrie	No designated session in job plan	NHS

Notes:

1. Dr Rachel Dommett was appointed as the new Lead Clinician from October 2016. Prior to this Professor Stevens was the Lead Clinician, appointed on a one year contract.

2. Dr Laura Baker has responsibilities to paediatric oncology and haematology services. Sue Dolby, Consultant Clinical Psychologist and Head of Psychological Health Services at University Hospitals Bristol has oversight responsibilities for the psychological support offered to the TYA service. In addition, she receives funding from Macmillan (0.1wte) to support a further contribution to TYA services through the On Target programme (to March 2016) and, since then, to the IAM Portal Project.

3. Following a bid submitted to Teenager Cancer Trust for an additional 1.0wte TYA specialist nurse, Claire Lewis-Norman was appointed in November 2016 with a view to commencing the role in January 2017. Claire will work alongside Jax Hulbert covering North Bristol Trust and Royal United Hospital Bath.

4. Fran Hardman was appointed to this new post, funded by Macmillan as a service development initiative, for 1 year from June 2015. Macmillan has since extended funding for this post by a further 11 months to May 2017. A bid was submitted to the Division of Specialised Services at University Hospitals Bristol in December 2016 to secure the long term funding of this post.

5. Hannah Pring was appointed in November 2016. This is a key role in the day to day operations of the TYA SW Cancer Service to ensure a seamless service at all times across the SW of England. The role will incorporate on-going regional projects, data collection, regional administrative support and will serve as a central point of contact for the TYA SW Cancer Service.

6. University Hospitals Bristol agreed to fund a new Consultant adult haematology post with specific responsibility for malignant haematology (leukaemia and Lymphoma) in TYA. Dr Caroline Furness was appointed in April 2016 as the TYA lead for adult haematology at the PTC and commenced in November 2016. This post has 2.5 PA (within a 10 PA job plan) allocated to TYA.

7. Following a successful bid UHBristol provided 0.5PA to each of the main site specific teams (Sarcoma, Germ Cell, & Neuro-oncology. A PA already existed in the job-plan for paediatric oncology.

8. There is no designated session for TYA within adult palliative care, although there is intention to address this in 2017.

3.2 At Designated TYA Hospitals across the TYA SW Network

All the TYA Specialist Nurses at the designated hospitals are funded by the NHS but the posts have been adopted by Teenage Cancer Trust.

A summary of the key roles involved in the delivery of TYA care at designated hospitals is shown in Table 2, below:

Table 2: Details of staff with TYA responsibilities at TYA designated hospitals

Role	**Post holder at 31.12.16**	**Full/Part time (wte)**	**Funded by**
Gloucestershire Hospitals NHS Foundation Trust			
TYA Specialist Nurse	Megan Wilsher	1.0wte	NHS & Cobalt[1]
TYA Lead Clinician	Dr Asha Johny	No designated session in job plan[2]	NHS
Social Worker	See note below[3]	-	CLIC Sargent
Royal United Hospital NHS Foundation Trust			
TYA Specialist Nurse	Jax Hulbert / Claire Lewis-Norman	As part of role at PTC[4]	NHS/Teenage Cancer Trust
TYA Lead Clinician	Dr Sally Moore	No designated session in job plan[2]	NHS

Taunton & Somerset NHS Foundation Trust			
TYA Specialist Nurse	Lorraine Beddard	0.5wte	NHS
TYA Lead Clinician	Dr Belinda Austin	No designated session in job plan[2]	NHS
Social Worker	See note below[5]	-	CLIC Sargent
Community Worker[6]	Daniel Honey	1.0 wte	CLIC Sargent
Royal Devon and Exeter NHS Foundation Trust			
TYA Specialist Nurse	Lorraine Beddard	0.5 wte	NHS
TYA Lead Clinician	Dr Peter Stephens	No designated session in job plan[2]	NHS
Social Worker	Richard Nobes	1.0 wte shared with Plymouth	CLIC Sargent
Plymouth Hospitals NHS Trust			
TYA Specialist Nurse	Kerry McKay[7]	0.5 wte	NHS
TYA Lead Clinician	Dr Hannah Hunter	No designated session in job plan[2]	NHS
Social Worker	Richard Nobes	1.0 wte shared with Exeter	CLIC Sargent
Macmillan Cancer Information and Support Specialist	Ellie Ricketts	0.5wte	Macmillan
Royal Cornwall Hospitals NHS Trust			
TYA Specialist Nurse	Hannah Heayn[8]	0.5 wte	NHS
TYA Lead Clinician	Dr Toby Talbot	No designated session in job plan[2]	NHS
Social Worker	Richard Nobes	1.0 wte shared with Exeter	CLIC Sargent

Notes:

1. Megan Willsher has a full time post funded jointly and equally by the NHS and by a local charity (Cobalt).

2. None of the clinical leads for TYA at the designated hospitals have a specific sessional commitment funded for this role. This has been discussed and noted at each of the individual hospitals TYA Steering groups.

3. There is no CLIC Sargent young person's social worker based in Gloucester. Support may be offered from Suzie Holmes who works as part of the PTC team in Bristol but equity in service access is not assured.

4. The workload at the PTC precluded Jax Hulbert's presence on site in Royal United Hospital Bath & North Bristol Trust on a routine basis. The successful bid submitted to Teenage Cancer Trust and consequent appointment of an additional TYA specialist nursing post (1.0wte) will address this deficit.

5. There is no CLIC Sargent young person's social worker based in Taunton. Support for patients in Somerset may be allocated to Suzie Holmes who works as part of the PTC team in Bristol, or to Lin Snell, the paediatric CLIC Sargent social worker

allocated to Taunton, or to Richard Nobes, CLIC Sargent social worker in Exeter and Plymouth.

6. Daniel Honey was appointed to a new post of Young Person's Community Worker in Somerset, funded by CLIC Sargent in 2015. He has a particular focus on supporting young people at and after the end of treatment.

7. Hannah Heayn left her post as TYA Specialist Nurse in Plymouth after return from maternity leave in 2015. The post was vacant at the end of the year but Kerry McKay took up her appointment to this post in February 2016.

8. The TYA Specialist Nurse post in Truro was vacant for much of 2015. Hannah Heayn (ex. Plymouth) was subsequently appointed to the vacancy and took up post in March 2016.

Of Note: With funding from Teenage Cancer Trust, recruitment continues across the Region. Lorraine Beddard will become 1.0wte TYA Specialist Nurse in Royal Devon & Exeter, a 1.0wte TYA Specialist Nurse will be appointed in Somerset and a 0.5wte Band 6 post has been agreed in Plymouth. There will be 8 TYA Specialist Nurses (6.5wte) in post by spring 2017.

4. CLINICAL ACTIVITY

197 patients were discussed at the MDaT in 2016; 163 were new to the MDaT, of whom 148 were newly diagnosed (i.e. 'new to cancer'). In the absence of detailed cross referencing against full regional cancer registration data, this can be estimated to represent approximately **87%** of the expected incidence of cancer in 16 – 24 year olds in the South West[1]. This is an increase from **66%** in 2015.

4.1 Diagnosis classification of patients discussed at TYA SW MDaT in 2016

Table 3 details the diagnostic classification of the patients discussed by the MDaT using the Birch classification[2], which is the accepted method for grouping diagnoses for TYA cancer (Table 3).

Table 3: Diagnosis classification of patients discussed by MDaT in 2016 using updated Birch classification.

		All	***New to MDaT & Cancer***
Leukaemia		**21**	**14**
1.1	Acute lymphoid leukaemia (ALL)	14	9
1.2	Acute myeloid leukaemia (AML)	6	4
1.3	Chronic myeloid leukaemia (CML)	1	1
Lymphoma		**36**	**27**
2.1	Non-Hodgkin lymphoma (NHL)	**12**	**10**
2.1.1	Non-Hodgkin lymphoma, specified subtype	11	9
2.1.2	Non-Hodgkin lymphoma, subtype not specified	1	1
2.2	Hodgkin's lymphoma (HL)	**24**	**17**
2.2.1	Hodgkin lymphoma, specified subtype	14	12
	2.2.2 Hodgkin lymphoma, subtype not specified	10	5
CNS tumours		**22**	**17**
3.1	Astrocytoma	**16**	**13**
3.1.1	Pilocytic astrocytoma	1	1
3.1.2	Other low grade astrocytoma	4	2
3.1.3	Glioblastoma and anaplastic astrocytoma	6	5
3.1.4	Astrocytoma not otherwise specified	5	5

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[1] 2011 national census data gave the population of the South West as 5.3m, of whom approximately 12% were aged 16 – 24 years, i.e. 636,000. The incidence of cancer in this age group is approximately 276/million, therefore the expected frequency of new cases of TYA cancer in the South West would be 170 – 180/year.

[2] Classification and incidence of cancers in adolescents and young adults in England 1979-1997. Birch et al. Br J Cancer 2002;87(11):1267-74.

3.2	Other Glioma	**3**	**3**
3.2.1	Oligodendroglioma	1	1
3.2.2	Other specified glioma	1	1
3.2.3	Glioma NOS	1	1
3.3	Ependymoma	**1**	**0**
3.4	Medulloblastoma / PNET	**1**	**0**
3.4.1	Medulloblastoma	1	0
3.5	Other malignant	**1**	**1**
3.5.1	Craniopharyngioma	1	1
3.6	Unspecified intracranial & intra-spinal neoplasms tumours	**0**	**0**
Bone tumours		**15**	**9**
4.1	Osteosarcoma	**10**	**5**
4.2	Chondrosarcoma	**1**	**1**
4.3	Ewing's sarcoma	**4**	**3**
4.3.1	Ewing sarcoma of bone	4	3
4.4	Other Bone Tumours	**0**	**0**
Soft Tissue Sarcoma		**22**	**15**
5.1	Fibromatous tumours	**1**	**1**
5.1.1	Fibrosarcoma	1	1
5.2	Rhabdomyosarcoma	**6**	**3**
5.3	Other specified	**15**	**11**
5.3.1	Liposarcoma	2	2
5.3.3	Synovial sarcoma	4	3
5.3.6	Nerve sheath tumours	1	0
5.3.8	Miscellaneous specified STS	8	6
5.4	Unspecified Soft Tissue Sarcoma	0	0
Germ Cell		**30**	**23**
6.1	Gonadal germ cell & trophoblastic neoplasms	**27**	**22**
6.2	Germ cell & trophoblastic neoplasms of non-gonadal sites	**3**	**1**
6.2.1	Intracranial germ cell and trophoblastic tumours	2	1
6.2.2	Other non-gonadal germ cell and trophoblastic tumours	1	0
Melanoma and Skin Carcinoma		**13**	**12**
7.1	Melanoma	**12**	**11**
7.2	Skin carcinoma	**1**	**1**
Carcinoma (excluding skin)		**28**	**23**
8.1	Carcinoma of thyroid	**7**	**7**
8.2	Other carcinoma of head and neck	**3**	**3**
8.2.3	Carcinoma of nasal cavity middle ear sinuses larynx and other ill-defined sites in head and neck	3	3
8.3	Carcinoma of trachea bronchus lung and pleura	**0**	**0**
8.4	Carcinoma of breast	**3**	**3**
8.5	Carcinoma of genito-urinary (GU) tract	**10**	**7**

8.5.3	Carcinoma of Ovary	7	5
8.5.4	Carcinoma of Cervix	3	2
8.6	Carcinoma of gastro-intestinal (GI) tract	**5**	**3**
8.6.1	Carcinoma of colon & rectum	1	1
8.6.3	Liver	1	0
8.6.4	Other GI sites	1	1
8.6.5	Carcinoma of other and ill-defined sites in GI tract	2	1
8.7	Other not classified elsewhere (NEC)	**0**	**0**
Miscellaneous specified neoplasms NEC		**5**	**3**
9.1	Embryonal Tumours NEC	**1**	**0**
9.1.3	Other embryonal tumours NEC	1	0
9.2	Other rare miscellaneous specified neoplasms	**4**	**3**
9.2.1	Paraganglioma & glomus tumours	1	1
9.2.4	Other specified neoplasms NEC	3	2
Unspecified Malignant Neoplasms		0	0
Non malignant		**5**	**5**
11.1.	Aplastic anaemia	1	1
11.2	Carcinoid tumour	2	2
11.10	Langerhans Cell Histiocytosis	1	1
11.12	MDS	1	1
	Total	**197**	**148**

Lymphoma (18%), Germ Cell Tumours (16%), Sarcoma (bone and soft tissue) (16%), CNS tumours (11%) and leukaemia (9%) represented the most frequent major diagnostic groups amongst those newly diagnosed.

Patients are referred to the TYA MDaT from a wide range of site specific MDTs and many are also discussed by more than one MDT before the diagnosis is confirmed and the treatment plan is agreed. Table 4 shows the referring MDT for 135 of the new patients to MDaT in 2016. This data was not collected for all young people.

The MDTs referring the largest number of patients were haematology, sarcoma, brain, skin and testicular.

Table 4: Referring MDT for all patients discussed by MDaT for the first time in 2016 (n=135)

	No. pts	***%***
Brain	12	9
Breast	3	2
Colorectal	3	2
ENT	1	1
Germ Cell	1	1
Gynaecology	8	6
Haematology	22	16
Head & Neck	9	7

Lung	2	1
Lymphoma	8	6
Neuroendocrine	3	2
Neuro-Oncology	3	2
Paediatric	7	5
Respiratory	1	1
Sarcoma	15	11
Skin	12	9
Skull base	1	1
Solid Tumours	1	1
Testicular	12	9
Thyroid	1	1
Upper GI	2	1
Urology	8	6
Total	135	

4.2 Patient demographics & completeness of data logged at TYA SW MDaT

Table 5 details the demographic profile of the 163 patients discussed for the first time by the TYA MDaT in 2016 and also provides an assessment of the completeness of data collection.

Table 5: Details of new patients discussed by TYA MDaT

DATA ITEM	***# of patients for whom data has been collected***	***% of patients for whom data has been collected***
Patients first discussed in 2016	**163**	**100%**
Male	70	55%
Female	93	45%
Ethnicity	**162**	**99%**
White British	146	90%
Age at Diagnosis	**163**	**100%**
0 – 15 years	13	8%
16 – 18 years	34	21%
19 – 24 years	115	70%
≥ 25 years	1	1%
Age at Referral to MDaT	**163**	**100%**
0 – 15 years*	5	3%
16 – 18 years	36	23%
19 – 24 years	115	70%
≥ 25 years	7	4%

Speciality of Consultant principally responsible for care at time of registration	**149**	**91%**
Paediatric Haematologist / Oncologist	14	9%
Haematologist	34	23%
Medical Oncologist	38	26%
Clinical Oncologist	18	12%
Adult Surgeon	36	24%
Other	9	6%

Cancer Pathway Point at 1st MDaT	**163**	**100%**
New diagnosis	148	91%
Recurrence	6	4%
Other	9	5%
Hospital centre registered from:	**163**	**100%**
Bristol	83	51%
Gloucester	15	9%
Bath	4	2%
Taunton	4	2%
Exeter	9	6%
Plymouth	31	19%
Truro	8	5%
Other (within SW)	6	4%
Other (outside SW)	3	2%

Clinical Trial Entry	**147**	**90%**
Yes	17	12%
No	130	88%
Reason given for non-recruitment?	**83**	**64%**
No trial available	74	89%
Trial available but ineligible	4	5%
Other reason	5	6%

	Male		**Female**	
Fertility preservation recorded	**60/70**	**86%**	**73/93**	**78%**
No impact expected	19	32%	32	44%
Insufficient time for intervention before treatment	1	1%	9	12%
Patient declined	6	10%	4	6%
Achieved	24	40%	16	22%
Other answer	10	17%	12	16%

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*Notes: * The age at referral changed during 2016 as detailed in section 2.1*

Data completeness has continued to improve, however these data suggest that the completeness of data collection in relation to reason for non-recruitment to a clinical trial and fertility preservation could be improved. With the introduction of IAM Portal South West Integrated Multi-disciplinary Management System (SWIMMS) data collection and completeness should continue to improve throughout 2017.

4.3 Data obtained from IAM assessments

The TYA service uses a holistic approach to understand the needs of patients following a diagnosis of cancer. We have developed the IAM (Integrated Assessment Map) as a TYA specific alternative to the Macmillan eHNA or other site specific holistic needs assessments in order to better capture information important to the care and support of young people with cancer.

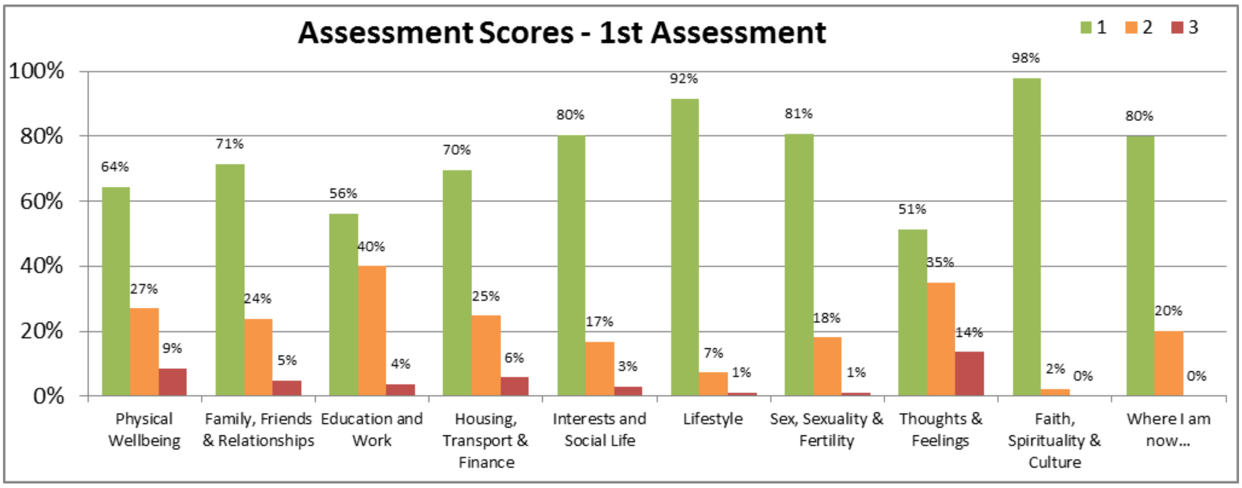
The IAM explores young people's needs in 10 domains, these domains have been identified by TYA as important and have an effect on their resilience and adaptation to cancer. Needs in each domain are assessed, if possible, by the young person themselves, with or without the support of a professional. Members of the TYA team, usually the local TYA Specialist Nurse, will explain the IAM to each newly diagnosed patient and provide them with a appropriate link to the IAM portal (a website offering the patient the ability to complete the IAM assessment and to access associated information and support). Each domain is scored on a four point scale (0-3 or green, amber & red) which indicates the level of concern and/or need for information and support expressed by the young person in each area.

107 of the 148 (72%) patients new to cancer and discussed for the first time in 2016 had an IAM (TYA Integrated Assessment Map) score recorded. Average scores and distribution are detailed in Table 6 and Figure 4.

Table 6: Average scores in each domain at first MDaT IAM assessment (all patients discussed in 2016). The IAM is scored on a three point scale 1-3 where 1 indicates no additional need and 3 identifies significant additional need

Average Score by Assessment	IAM Assessment 1
Physical Wellbeing	1.4
Family, Friends & Relationships	1.3
Education and Work	1.5
Housing, Transport & Finance	1.4
Interests and Social Life	1.2
Lifestyle	1.1
Sex, Sexuality & Fertility	1.2
Thoughts & Feelings	1.6
Faith, Spirituality & Culture	1.0
Where I am now…	1.2

Figure 4. The distribution of IAM scores in each of the domains recorded at the first IAM assessment for all patients discussed by MDaT in 2016



Towards the end of 2016 the service started transitioning data collection to the IAM Portal SWIMMS system. As collection of data from IAM scores continues to increase, it will become possible to undertake sub analyses by variables such as gender, diagnosis, age, cancer pathway point etc.

Highest level of need was identified in the thoughts and feelings domain with 35% scoring level 2 and 14% level 3. In education and work 40 % scored level 2 and 4% level 3.

4.4 Clinical Psychology Provision

The Clinical Psychology provision into the Teenage and Young Adult (TYA) service during this year was 0.4 wte Band 8a Specialist Clinical Psychologist (SCP), 10 months temporary wte 0.2 band 7 clinical psychologist plus the 0.1 wte management and IAM Portal Project time from the Consultant Clinical Psychologist.

During the period between January 2016 and December 2016, 44 referrals were accepted for specialist and targeted direct clinical work with TYA's and their networkers. 28 referrals were seen as outpatients with
90 follow-up appointments. The average number of follow up sessions were 6.8. 16 young people were seen as inpatient referrals with 89 follow-up appointments, an average of 5.5 follow-up sessions. This data excludes some indirect (non face-to-face) patient-focused work (e.g. time spent preparing therapeutic resources, or preparing reports/referrals to other appropriate services). 37 appointments were not attended with the reason unknown and 17 appointments were cancelled.

Reasons for referrals included: emotional adaptation and adjustment to a cancer diagnosis and treatment, procedural management, concordance with treatment, anxiety and depressed mood, anger difficulties, eating related difficulties, behavioural difficulties related to treatment and its effects, appearance related concerns, trauma related difficulties, managing the palliative care stage and immediate bereavement support. Contacts have ranged from initial only assessment and/or signposting appointment to longer-term therapy

In addition to the above, a range of indirect services were offered to provide consultation , training and clinical supervision for non specialist psychology staff to enhance the psychologically informed care provided by the TYA and site specific multi-professional teams caring for TYA. This included attendance at the weekly TYA MDaT meeting, a monthly reflective practice for the TYA team and individual one to one clinical supervision of the TYA Youth Support Co-ordinator (YSC) and TYA Well-being Co-ordinator. Additional psychological consultation and supervision regularly took place with other MDT members as required. The SCP takes a leading role in liaison with appropriate local and regional services (e.g. Mental Health Services and bereavement services) to ensure continuity of care and access to local services as needed.

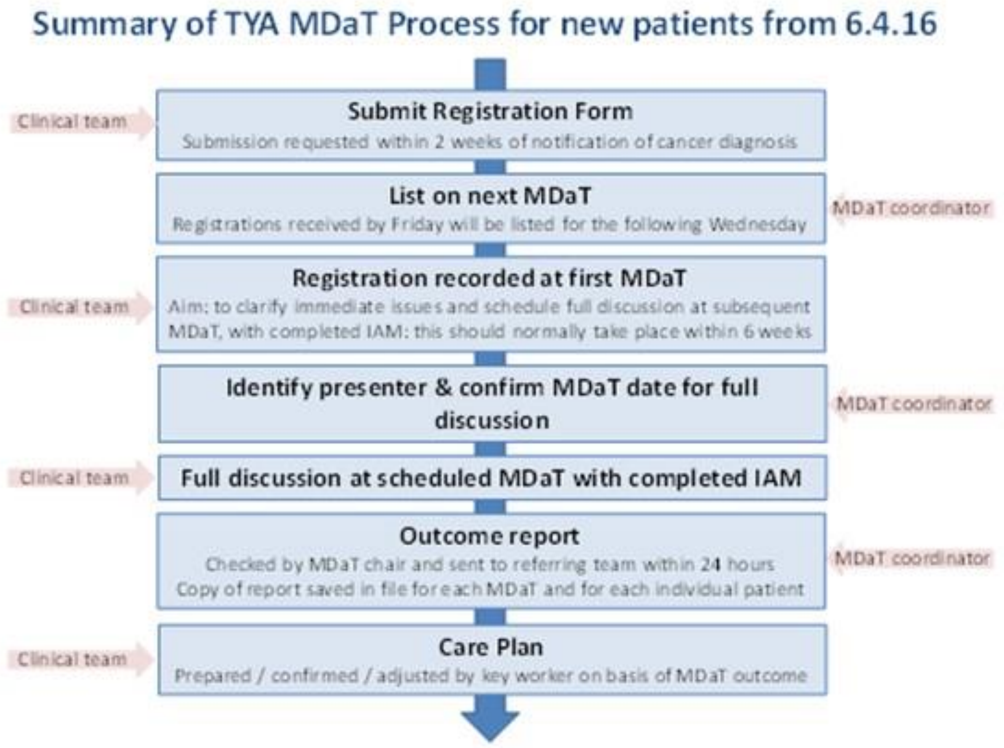
Teaching and training provision has included the following TYA events: Strictly TYA, University West of England TYA day, regional TYA study day, Teenage Cancer Trust Study day and 'The Way Forward' event. The SCP has worked jointly with the TYA Wellbeing Coordinator to develop a wellbeing course 'living well' for TYA networkers in partnership with Penny Brohn, this course successfully ran twice, received good feedback and a poster was presented at the international TYA conference in December 2016. Clinical psychology has had continued involvement in the development of the TYA Integrated Assessment Mapping (IAM) Portal which includes access to supported self-management to build emotional resilience and psychological wellbeing as well as an electronic holistic needs assessment. The SCP supported the TYA patient experience survey for both patients and networkers in line with peer review standards.

Objectives for psychology provision in 2017-18 include continuing to contribute to service developments, research and national TYA psychology network. The SCP will also offer a placement for a clinical psychologist in training. In February 2017 there will be a permanent increase in Band 7 sessions for TYA provided by Psychological Health Services based in the Bristol Haematology and Oncology for TYA and Adults with cancer.

5. EVOLUTION OF THE MDaT

The TYA SW MDaT takes place as an online WebEx meeting and is held weekly on Wednesdays from 12:30-14:00. The referral of new patients was reviewed at the end of 2015 and is now managed as a two-step process.

Figure 5. summarises the process:



Summary of TYA MDaT Process for new patients from 6.4.16

Submit Registration Form
Submission requested within 2 weeks of notification of cancer diagnosis

List on next MDaT
Registrations received by Friday will be listed for the following Wednesday

Registration recorded at first MDaT
Aim: to clarify immediate issues and schedule full discussion at subsequent MDaT, with completed IAM: this should normally take place within 6 weeks

Identify presenter & confirm MDaT date for full discussion

Full discussion at scheduled MDaT with completed IAM

Outcome report
Checked by MDaT chair and sent to referring team within 24 hours
Copy of report saved in file for each MDaT and for each individual patient

Care Plan
Prepared / confirmed / adjusted by key worker on basis of MDaT outcome

First, referrers are asked to register the patient by completing a registration form available on our website and emailing it to the MDaT Coordinator at UH Bristol. The registration is listed at the next available MDaT so that the wider team are aware of the patient and to ensure that immediate needs are addressed. A date is suggested for a full discussion at a later meeting, usually within 6 weeks. The MDaT coordinator will then liaise with the referring team to obtain further information about the patient and to confirm the best date and time for them to join the MDaT for the full discussion about the patient.

At the full discussion, the chair of the MDaT (usually the TYA Lead Clinician or TYA Lead Nurse) facilitates a short presentation from the referring team around the patient's diagnosis, prognosis and treatment plan and will ask about recruitment to any available clinical trial and whether or not fertility preservation was necessary, possible or implemented. The patient's holistic needs are then discussed, using the IAM (Integrated Assessment Map) submitted prior to the meeting to structure the conversation. If the young person has not submitted their own IAM, or one done in partnership with a healthcare professional, the key worker is asked to submit a professionally led IAM before the MDaT discussion.

The outcomes and actions from the meeting should be used to inform the patient's care plan and are emailed (via nhs.net) to the referring team by the MDaT coordinator as a pdf document which can be downloaded to electronic medical records and/or printed and filed in the patient's notes. This includes a date for review at a future TYA MDaT if this has been agreed to be appropriate. All patients are routinely reviewed at/around the end of treatment.

Table 7 shows the attendance by core members of the TYA MDaT at the 44 MDaT meetings held during 2016. Target attendance by individual core members of the TYA MDaT is 66%.

Attendance was achieved at a low level by medical staff from the key adult site specific MDTs: this relates to previous absence of designated sessions in consultant medical staff job plans. This has now been addressed. It is anticipated that attendance by site-specific consultants will improve following this investment in 2017.

Table 7: Attendance by core members of the TYA MDaT

Role	**Name**	**% Meetings attended (n=44)**	**Dates in post if not for whole year**
TYA MDaT Coordinator	Rebecca Mathias or Megan Butcher	100%	
Lead Clinician	Rachel Dommett	86%	In post as Lead Clinician 01.10.16
Lead Clinician	Mike Stevens	76%	In post from 01.01.16 to 29.09.16 (n=33)
Lead Nurse	Jamie Cargill	75%	
TYA Specialist Nurse (Bristol & Bath)	Jax Hulbert	71%	
Clinical Psychologist	Laura Baker or Sue Dolby	90%	
Youth Support Coordinator	Hannah Lind	84%	
CLIC Sargent Social Worker (Bristol)	Suzie Holmes	80%	
Adult haematology MDT	Haematology– Dr Furness	83%	In post from Nov 2016 onwards (n=6)
Adult germ cell MDT	Germ Cell Dr Kuchel	30%	0.5PA from October 2016 (n=10)

Adult CNS MDT	Brain Dr Maclean	40%	0.5PA from October 2016 (n=5)
Adult sarcoma MDT	Sarcoma Dr Dangoor	10%	0.5PA from October 2016 (n=10)

Attendance of non-core members of the MDaT according to Peer review

Wellbeing Coordinator	Fran Hardman	80%	
TYA Specialist Nurse (Taunton & Exeter)	Lorraine Beddard	72%	
TYA Specialist Nurse (Gloucester)	Meg Wilsher	80%	
TYA Specialist Nurse (Truro)	Hannah Heayn	76%	In post from 01.03.16 onwards (n=37)
TYA Specialist Nurse (Plymouth)	Kerry McKay	69%	In post from 01.02.16 onwards (n=36)
Social Work Team Leader South West	Rachel Banks	65%	
CLIC Sargent Social Worker (Exeter/Plymouth/Cornwall)	Richard Nobes	50%	

6. MANAGING THE NETWORK

A description of the service is provided in Section 2 of this report. Major points considered in discussions over the year about the integrity of the TYA SW network included:

- a recognition that the referral of all patients for discussion at the TYA MDaT was core to the management of the service
- endorsement of the original decision, taken in 2011, to commission the service as a network of care despite incomplete compliance with the expectations of the IOG with regard to place of treatment
- an acknowledgement of the challenges involved in ensuring that TYA patients were offered appropriate choice about place of treatment
- the need for reinvigoration of the role of the TYACNCG (TYA Cancer Network Coordinating Group), and a review of its membership.
- recognition of the following statement about the networking of care, published as an Appendix to the TYA Peer Review Measures, as a key value for the management of the TYA SW service:

  "They (rules for networking) allow the development of consistent, intra- and inter-team patient pathways which are clinically rational and in only the patients' best interests instead of in the vested interests of professional groups or of NHS statutory institutions".
- the need to review the existing age thresholds which define the TYA service, specifically in relation to the interface with paediatric services.

It is also now clear that none of the TYA lead clinicians at the designated hospitals have time adequately identified and available within their job plans to fulfil this role. Whilst it would be expected that the appointment of a network coordinator would support some of the organisational issues involved in participation in the network, all clinical leads need more time to promote and engage with colleagues in their own hospitals over the issues relating to TYA care, and to develop local services. The place of the TYA steering groups held at designated hospitals was reviewed and reinforced. These meetings serve to keep local hospital trust management informed as well as ensuring a regular interface between the TYA network lead and the TYA Lead Clinician and Lead Nurse.

An action plan was developed within the TYA annual work programme to address these issues which is being taken forward in 2017. Work was also initiated to improve data collection, including hospital and MDaT activity information.

7. PEER REVIEW

7.1 Previous areas of non-compliance

Non-compliant measure	**Update on action to address**
Other staffing (AHPs)	Wellbeing Coordinator appointment extended until May 2017. This will greatly improve access to AHPs and provided some dedicated AHP staffing
MDT quorum (due to policy of members attending for relevant cases only)	MDaT SOP changed to reflect the need for site-specific medical representation supported by UHBristol. Job plan have been changed and Adult Haematologist with specific TYA responsibility has been appointed
MDT attendance (due to policy of members attending for relevant cases only)	As above

7.2 Previous concerns

Concern	**Update on action to address**
Lack of dedicated AHP support, as per measure	As above

8. PATIENT EXPERIENCE

8.1 Feedback

The annual patient and networker (defined as family, friends and others close to the patient) feedback questionnaires were disseminated across the region at the beginning of February 2017 and remained open online until March 2017. The TYA specialist nurses were crucial to maximising the response rates of these questionnaires and ensuring that feedback was received from across the South West. A full report is available on request.

45 TYA patients from across the region responded to a questionnaire which was made available on line and also offered in paper form by request. Responses were received from across the region, however Bristol was the main treating hospital in 44% of responses. Areas with particularly positive feedback were related to: helpful information being provided, patients being given an opportunity to ask questions, overall experience of the TYA service, feeling listened to by TYA staff and understanding the role of TYA staff. 80% reported an excellent experience of the TYA SW Service. Nearly 50 % of young people expressed that their cancer diagnosis had a high impact on their 'wellbeing'. Responders also expressed increased difficulties in relation to 'spare time and leisure activities' and 'social life'. These findings are illustrated below in figures 6,7 & 8.

Figure 6. illustrates the main treating hospitals of responders

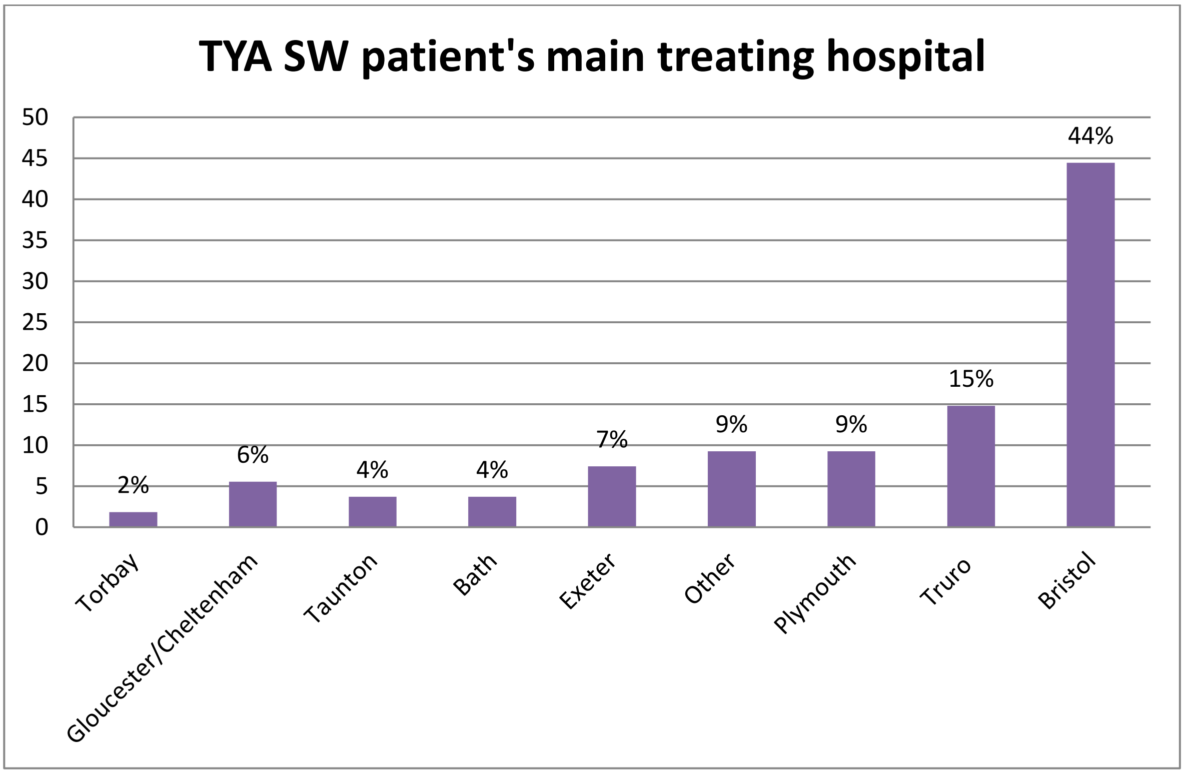


Figure 7. illustrates experience of the TYA Service as rated by patients

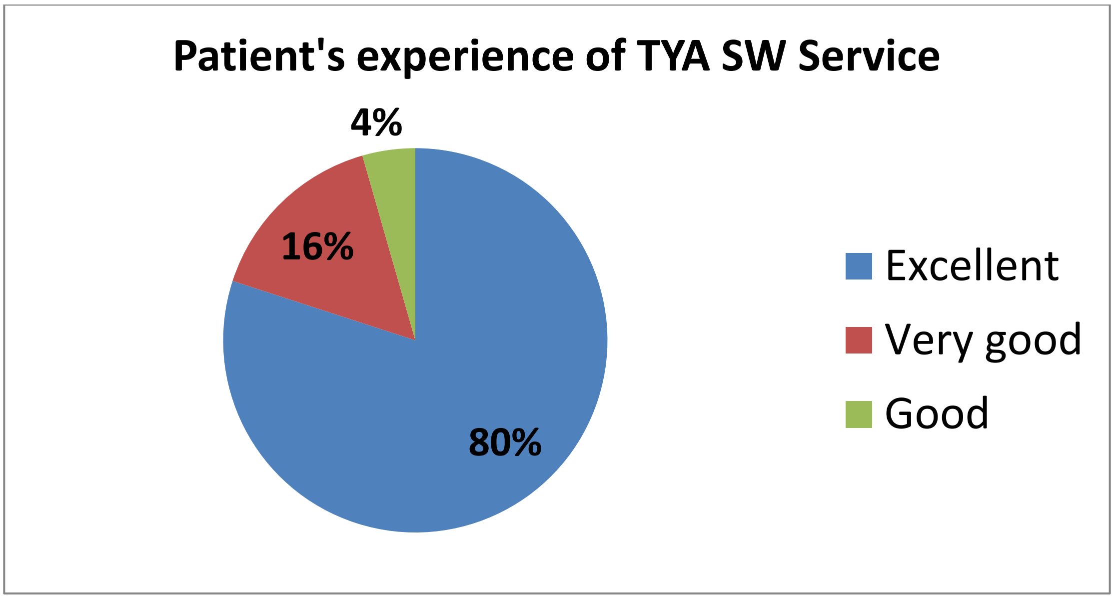
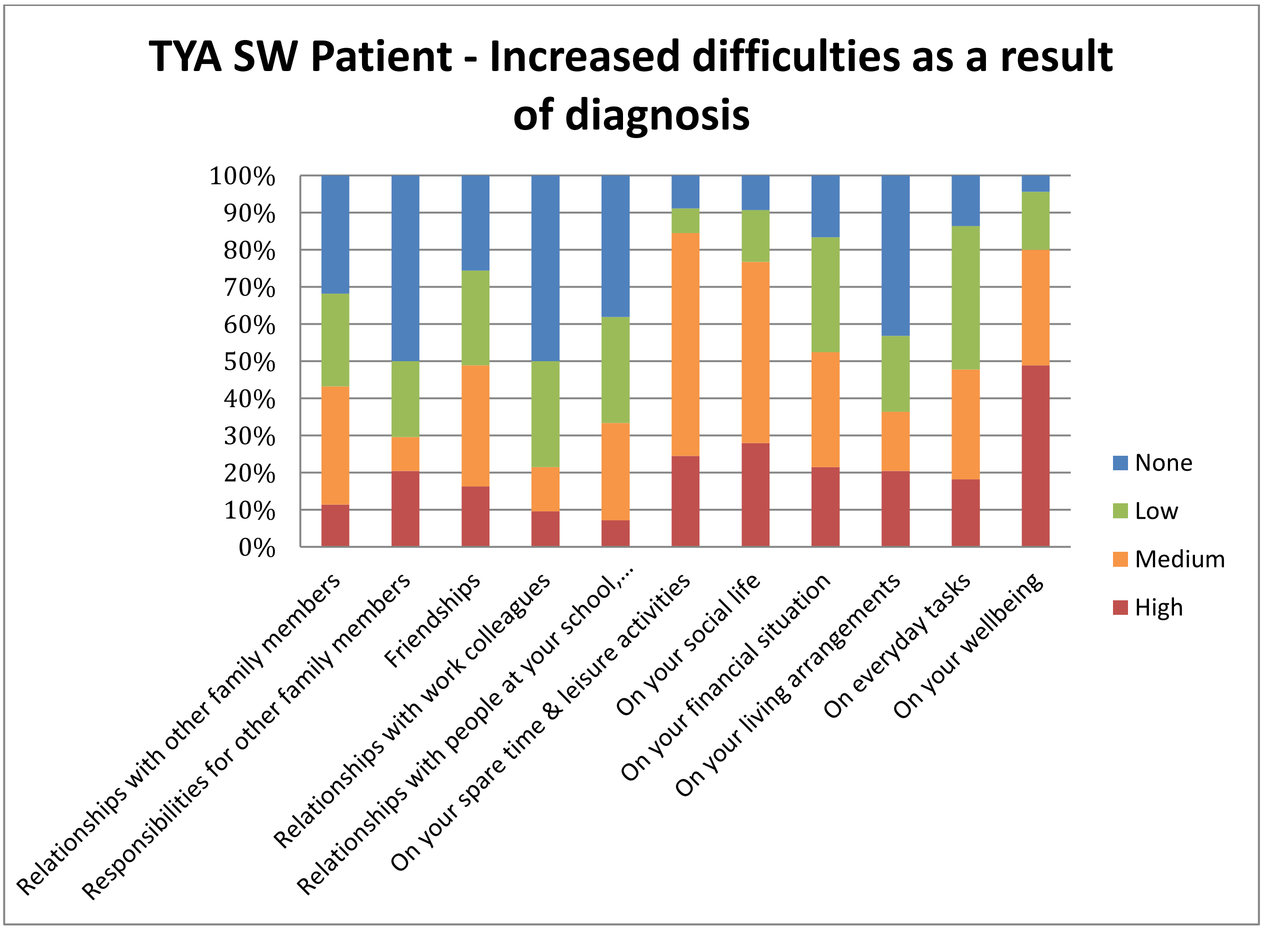


Figure 8. illustrates the level of impact as a result of the cancer diagnosis on various areas of life as rated by patients



Patients were also offered an opportunity to provide free text comments, the overwhelming majority of which were positive;

- “The TYA Service was great for me. It allowed me to meet people around my age who had gone and were going through cancer treatment. It helped me to be more social and get out of the house with all their activities. They provided reflexology that was relaxing and helped with my mental stresses as well as any physical stresses through treatment. The CLIC Sargent workers gave additional charity contacts that were activities to look forward to post-treatment.”
- “An ideal service for someone like me who lives away from home, at university. A perfect environment, which makes me feel comfortable, relaxed and feeling good in general towards my treatment”
- “The TYA Team in Bristol have been brilliant and offered so much support to me and my family. They also provide an essential link to support that I have from the Truro team. Area 61 has been really well designed for the needs of young people…”

In summary areas for continued development in 2017 include how treatment options were explained, patients feeling listened to by all hospital staff and responding to the specific wellbeing needs of young people.

35 ‘Networkers’ also responded to a separate questionnaire which focused mainly on an assessment of their own needs rather than their views of the TYA service; 31 of these were parents. 72% of networkers felt they received enough help in supporting their young person. This therefore remains an area of possible development for the service. The development of Living Well, a residential programme for the supporters of TYA’s, will hopefully help to address this. Networkers indicated that the main areas where help or support was needed were ‘information about the illness’ and ‘emotional support.’ These responses are illustrated below in Figure 9 & 10.

Figure 9. illustrates whether patient networkers felt they received enough help supporting patients

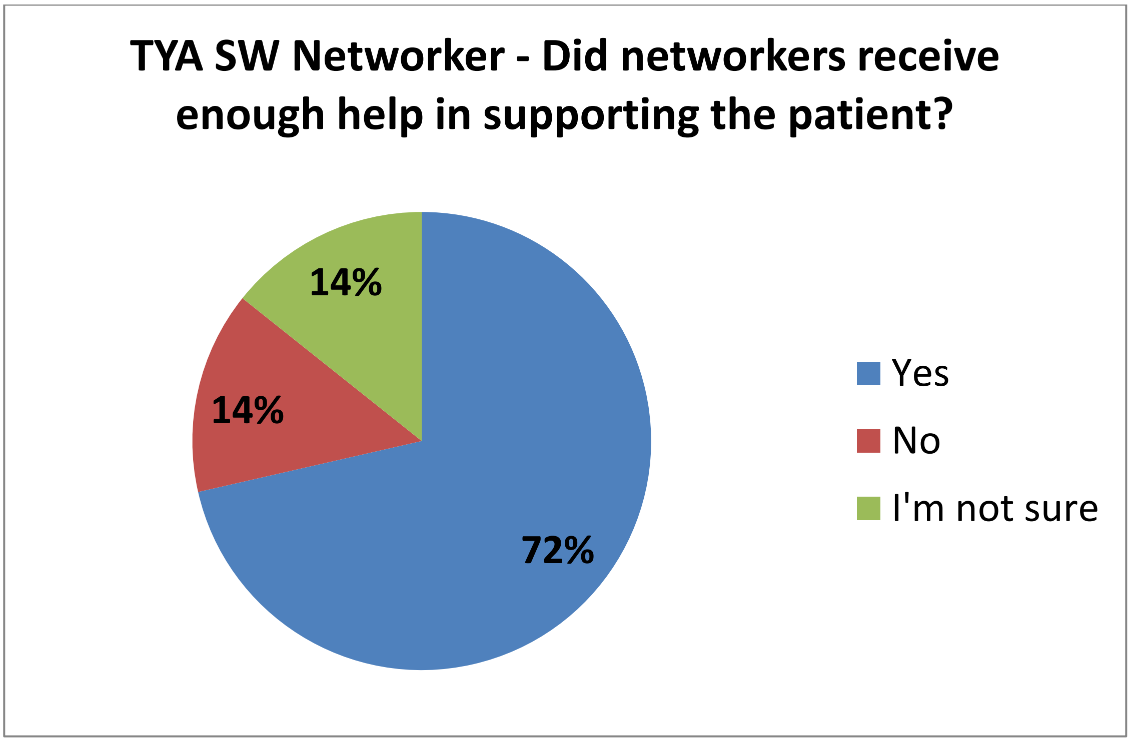
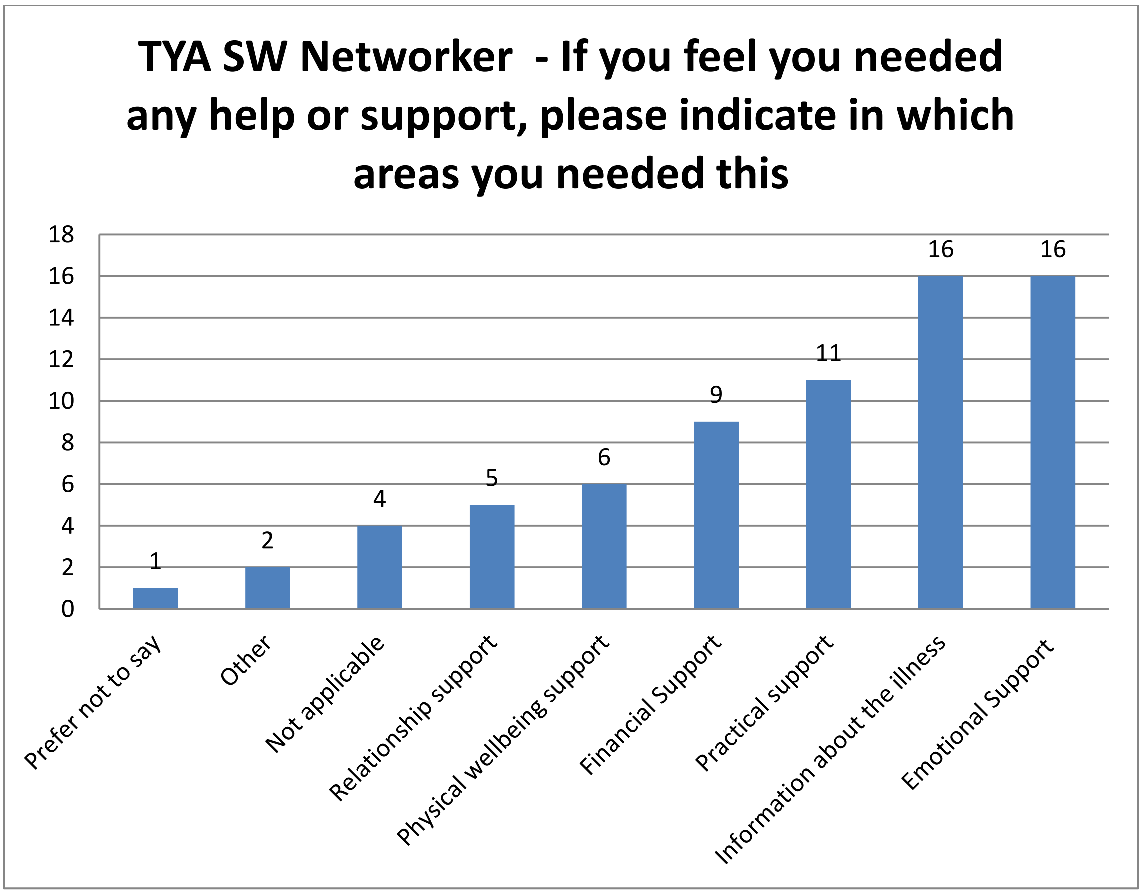


Figure 10. illustrates areas of help or support networkers needed



Networkers were also offered an opportunity to provide free text comments, the overwhelming majority of which were positive and also highlighted the importance and impact of charity partners;

- “From very early on we decided we would need to accept support from anything that was offered. The TYA Team and CLIC Sargent have been absolutely invaluable. Macmillan is also a fantastic charity and we are so very grateful to them. CLIC House has been the perfect "advanced base camp" for us. Thank you to all and a big huge thank you to TYA for coordinating it all.”

8.2 Healthwatch

Healthwatch is the official framework through which local people can have their say about health and social care services. Healthwatch works on behalf of the whole of the community – children, young people and adults. Healthwatch are able to feedback patient experiences to services and hold them to account; it can also enter and view services such as care homes and hospitals, observe what is happening and report back to commissioners.

Healthwatch Bristol were invited to visit the TYA unit at BHOC as a follow up to a previous engagement session in 2015. Young people, friends and family were able to feedback about support being delivered, as well as other experiences of accessing health and social care services in Bristol in general. Below is a short summary of the findings; the full report is available upon request.

What is your experience of asking for or receiving emotional support alongside your treatment?

- All the group members said that the emotional support on the unit has been really good and has really helped them along their individual journeys to understand their condition better.
- The group praised the work of the support worker and said it was good having them there during appointments as it had help them feel more comfortable during medical appointments.
- One young person had specially asked to be treated at Bristol and they felt that the support and environment was better than in the Hospitals.
- Some members said that they enjoyed the music session as it did not feel like support but just relaxing with music adding that they felt these sessions where therapeutic.

What do you value most about the support you have received?

- All said that it was good to speak to other peers who have undergone the same treatment and this was a good support when they had the chance to get together at events and in sessions which provided the opportunity to discuss their experience of treatment and care.
- All said that the emotional support was beneficial for them as patients and their families. They particularly said the reflexology for their parent’s just to have a time when they could also chill and relax was good.

- All felt that staff where very understanding and would help to break down explanations of conditions and treatment so that the patients and family felt well informed.

What services would you like to receive before or after you finish treatment?

- “The meeting and socialising events with other people who have undergone the same treatment was a good support line.”
- To continue being invited/informed about gatherings for patients even after the treatment and being discharged so that there was an opportunity to continue with the support/activities.
- Physiotherapy

The comments below highlight areas where improvements can be made; in particular relating to staffing and timely chemotherapy/medication.

‘Commentators mother said that the support and care her daughter receives is of a high standards. She said that living in Gloucester, she knew that they could access the Hospital 24/7 as well as the telephone support and felt that this was reassuring to know. She did add that there could be improvements in the night shift staffing and felt that they are under staff during times and thought that there should be two medical staff present during this particular shift.’

‘Commentator’s father felt that on occasions when her daughter came in for chemo treatment the medication should be ready and available, however there has been times when they have had to wait for medication to arrive from the pharmacist before she is able to undergo treatment. He felt this is insufficient and can result in long delays and having to stay in Hospital longer durations than necessary had this been organised before.’

‘The commentator said that the chemotherapy medicines should be planned and prepared before he comes in for treatment and on occasions when medication has not been ready, he leaves the hospital untreated as he dislikes the delays which can cause him unnecessary stress. He said that when he does have his chemo he prefers to have a familiar nurse. “The nurses’ are really good and as I have not always been the best inpatient!” he says that they talk to him like an adult and that has been encouraging.’

8.3 Activities and Peer Support

The Teenage Cancer Trust Youth Support Coordinator is responsible for a programme of activities within the PTC which offer TYA patients the opportunity for peer contact and support through social activities. Currently, around 100 young people are on her active contact list. She has met most of them, engages regularly with at least half and has a small number that she sees on a regular, daily (when in hospital) or weekly basis.

Planned group sessions happen 2-3 times a week with spontaneous sessions arranged depending on who is in the TYA unit. Regular activities include afternoon tea (every week) and music therapy sessions (every fortnight). Other regular group events are arranged quarterly, for example “Look good feel better” sessions and

Fimo(modelling) workshops; intermittent activities include lots of art workshops and a monthly social/ peer support group which has included meals out, bowling, escape games and comedy gigs

"Raft building was awesome and hot! We had a lot of fun working as a team to build an unsinkable vessel and it worked!! We managed to paddle around the river at Hotwells and played some games on the water too, did I mention it was hot?!?!"

One to one sessions are organised on an 'as required' basis and usually arise if a young person needs specific advice or support around a particular aspect of their life, for example, discussions about job seeking or volunteering opportunities. One to one support is prioritised for in patients who are bed bound or in isolation and when a young person doesn't have much support from friends or family.

This support is highly valued, as illustrated by these quotes from young people:

"I just wanted to thank you for all of your efforts both in organising my trip to Find Your Sense of Tumour (FYSOT) and in all the other workshops you have organised. You always have a smile on your face and you always do what you say you will."

"Without the events organised by the youth support coordinator I wouldn't be as confident as I am now, and having an amazing time too!"

Each of the designated hospitals host similar activities facilitated by the TYA Specialist Nurses, CLIC Sargent colleagues and volunteers. This constitutes social activities that include evening meals, outdoor activities & music groups. An example of the success of these initiatives was when two social events occurred on the same evening in Plymouth and Exeter, with 40 young people attending in total. All events and social activities are funded and supported by Teenage Cancer Trust, CLIC Sargent and local charities

Young People across the south west attended the Teenage Cancer Trust FYSOT weekends (under and over 18yrs), Ellen MacArthur sailing trips, & Royal Albert Hall gigs hosted by Teenage Cancer Trust

9. EDUCATION & TRAINING

The TYA SW service has always prioritised the provision of training opportunities for staff involved in TYA care.

9.1 Study Days

"Strictly TYA"

In 2010, a learning needs analysis was conducted of all staff involved in the care of TYA within UHB. This resulted in the development of a multidisciplinary teaching course entitled 'Strictly TYA'. The aim of this study day is to explore the normal physical, psychological and social development of teenagers and young adults and appreciate the effect cancer has on these areas. The content includes the physical, psychological and ethical aspects of TYA care plus issues of policy, communication and transition.

In a similar format to that of 2015 a 'Strictly TYA' study day was delivered in March 2016. Overall 22 regionally based multi-professional delegates attended the study day in 2016. All either agreed or strongly agreed that they had "learnt a lot from the study day" and all "would recommend to their colleagues".

"A brilliant and informative day. I rotate working with TYA and adults and sometimes find it hard to build relationships with TYA patients because of issues relating to their age. This day has helped me understand TYA patients and their expectations. Found it great that past/present TYA patients were here"

"Working with Teenagers/Young Adults with Cancer"; a one day learning event hosted by TYA Cancer Service South West at UHBristol in conjunction with Teenage Cancer Trust and Coventry University. 40 professionals attended with topics covered on the day similar to those covered as part of the 'Strictly TYA' programme.

9.2 Other teaching / training

Members of the team continue to contribute in the delivery of age specific training in a number of higher institutions including Coventry University, Cardiff University, Plymouth University and University of the West of England (UWE).

9.3 Conference Presentations

In December 2016, eight members of the Bristol TYA team and the IAM Portal programme (see section 10) attended the Teenage Cancer Trust 9th International

Conference and 1st Global AYA Cancer Congress in Edinburgh, giving four presentations on work done by the TYA SW Clinical Service. The abstract titles were:

- ”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. (Oral presentation by Rachel Dommett)
- App based technology to increase young people’s use of the IAM: A TYA specific holistic needs assessment (Poster)
- A pilot study to investigate the effectiveness of a two day wellbeing course for teenage and young adults (TYA) supporters(Poster)
- Jamie Cargill (Teenage Cancer Trust Lead Nurse Teenage and Young Adults (TYA) South West) presented on Integrated Assessment Mapping (IAM) during the session ‘Challenges of Communication and Engagement’.

Other conferences the team have contributed to included:

- Macmillan Practice Nurse Cancer Course (April 2016)
- TYAC Conference – Fertility in TYA Care
- Macmillan GP academic meeting (Penny Brohn UK) (September 2016)
- Sarcoma UK Nurses academic meeting (September 2016)
- Brigstow Bristol University Launch, BBC Natural History in 360 in TYA Care

Members of the “Too Young to Get Cancer?” team also attended and contributed to meetings for the Accelerate, Coordinate, Evaluate (ACE) Programme – Vague Symptoms Cluster.

9.4 Publications

The Blueprint of care for teenagers and young adults with cancer 2nd Ed Chapter 6 Holistic Needs and Supportive Care, **Cargill, J, Cheshire, J & Hewett-Avision**, S; Dec 2016

10. SERVICE DEVELOPMENT AND AUDIT

10.1 IAM Portal Project

TYA IAM

Work done by the TYA SW cancer service team developed the concept of an age specific, multi-domain framework for HNA which would provide a structure to ensure that all young people were offered assessment and that review discussions incorporated the impact of, and adjustment to, their cancer and its treatment within a bio-psycho-social-educational-vocational framework i.e. what does having this cancer and its treatment mean for this young person and their support network at this point in time. Once implemented, work was further developed in partnership with the Macmillan funded TYA On Target Programme her at UH Bristol resulting in the development of the TYA specific Integrated Assessment Map (IAM) which has now been developed for access via a website (www.tyaiam.co.uk) and, this year an app for use on all mobile devices.

TYA Help website

Other work within the TYA On Target Programme led to the development of a website offering young people access to advice and information to support emotional and psychological wellbeing (www.tyahelp.co.uk). This derived from work with young people themselves who highlighted the lack of such resources and the value of access to age appropriate, cancer specific support of this kind. The resources have been broadened over the last year to incorporate the other domains of the IAM, and to increase the multi-media presentation of information.

TYA SW IAM Portal Project

The separate but parallel development of the TYA IAM and the TYA Help website was governed by the same key principles, particularly by the engagement of young people in a co-creation / co-design process in developing both solutions. In that context it became clear that the integration of holistic needs assessment with a resource for self-management would better meet the needs of young people. Furthermore, as the TYA IAM had also become the framework used to structure the discussion of young people's needs at the TYA MDaT (Multi-Disciplinary advisory Team) meetings, the ability to capture IAM scores as an indicator of patient need was recognised as a valuable tool to influence service development. This led to the development of an MDaT management system and data base – TYA SWIMMS (TYA South West Integrated MDaT Management System)

The integration of the TYA IAM with the TYA Help website, now expanded to include rich sources of information about all aspects of TYA cancer experience (much of it utilising material developed and presented by young people), and linked to SWIMMS now constitutes the TYA IAM Portal Project.

The ‘package’ offers:

TYA patients individual access to an age specific holistic self-assessment tool through which they can explore and document their needs *and* obtain information and support from an integrated framework of resources for self-management

TYA clinical teams: access to individual patient self-assessments (released only by patient permission) which can inform MDT and other discussions and from which individualised care plans can be formulated. Professionals will also have access to the Portal for the same wide range of information and resources for use in the support of TYA and their families.

TYA services and provider Trusts: access to a database for managing MDT activity and documenting its discussions, and for reporting activity, analysing patient need and assessing service demand

The NHS and its Voluntary Sector Partners: access reports of aggregated data from anonymised patient records providing a profile of TYA patients and their needs.

Ongoing

The TYA IAM Portal Project is reaching final evaluation in the TYA SW cancer service network has been piloted with colleagues in the East Midlands TYA service this year. Following the successful pilot of the IAM Portal from University Hospitals Bristol, the project is being taken forward and rolled out nationally by Teenage Cancer Trust, in partnership with Macmillan Cancer Support. University Hospitals Bristol will continue to host the project within the South West TYA Cancer Service and will provide the national organisations with continued support in the development of the project.

10.2 Wellbeing

Work done in the Macmillan-funded On Target programme involved an extensive assessment of the needs of TYA patients, their support network and the professionals working with them across the South West. A number of key issues emerged which, it was felt, would be best by the appointment of a specialist TYA Wellbeing Co-ordinator. These issues addressed:

- The ability of the service to apply the concept of the Recovery Package in a TYA appropriate way
- The need for TYA patients and their supporters (family, friends and carers) to gain earlier access to information and support regarding wellbeing issues such as the importance of remaining active and how to optimally manage symptoms such as fatigue and brain fog.
- The importance of offering TYA patients and their supporters the right amount of information in a variety of formats which are appealing and meaningful to young people, particularly as currently there is little detailed information on wellbeing issues that has been produced specifically for the TYA audience. This also links with work being done to enhance the content of the Help! website as part of the Bristol IAM Portal project.
- Better access to Allied Health Professional expertise (physiotherapy, occupational therapy and dietetics) particularly as work done by the On Target programme highlighted the need for AHP staff to adopt a different approach to the support of TYA patients.
- Support for TYA support network. In the On Target programme, young people made it very clear that they would feel better able to cope with their situation if they knew that their supporters could access support for themselves. No formal structure was available to offer those supporting young people with cancer the support they themselves need.

Work undertaken to the end of 2016 included the following initiatives:

- Plans for the funding and development of a Wellbeing Room in the TYA inpatient unit
- TYA Reflexology pilot (funded by Teenage Cancer Trust and Above & Beyond) – **report is available**
- Development and implementation of wellbeing screening and AHP input for all patients at diagnosis and as required through treatment
- Post-treatment sessions with young people who require additional support, focusing on physical and psychological wellbeing
- Parent group established.
- Planning and marketing of The Way Forward event as a joint initiative with Teenage Cancer Trust – **report is available**
- Development of Living Well (a residential programme) pilot for the supporters of TYA's – **report is available**
- Teaching re wellbeing on Strictly TYA study day
- Co-creation work with young people in the development of physical wellbeing resources for the Help! Website

10.3 'Too Young to Get Cancer?' National ACE programme project

A62 Too Young to Get Cancer - Bristol

Overview

The Too Young to Get Cancer project was a clinical audit and evaluation to map the diagnostic pathway of 16-24yr olds referred to the South West Teenagers and Young Adults (TYA) multi-disciplinary advisory team at University Hospital Bristol. The aim was to build an evidence base to inform future research and design of potential interventions; and to improve the time to diagnosis and the diagnostic experience for TYA.

Context

Cancer is the most common cause of disease related death in young people in the United Kingdom (accounting for 9% of all deaths in males and 15% of all deaths in females aged 15–24) yet it is uncommon, accounting for less than 1% of cancers at all ages (CRUK, 2013). Despite the fact that there are limited data to link prolonged time to diagnosis (TTD) with adverse outcome there is clear evidence that young people and their families highlight delay in achieving diagnosis as a major concern.

The project proposed that a better understanding of the referral pathways used by TYA patients across the regional network would help identify ways in which delays may be minimised in the future.

Aim and Objectives

1. To better understand the referral pathways used by TYA with cancer across the South West.
2. To define and inform the design of interventions to improve TDD in TYA cancer.
3. To disseminate findings within the primary and relevant secondary care communities in the South West and highlight the presentation and appropriate referral of TYA with suspected cancer.
4. To share lessons learned with other TYA services in England.

Description of audit

The records of 104 teenagers and young adults referred to the TYA multidisciplinary advisory Team at University Hospital Bristol over an 18 month period between October 2014 and April 2016 were audited.

The current status of each young person was verified by their TYA Clinical Nurse Specialist (CNS) or other relevant healthcare professional. Following verification, any young person who was deemed inappropriate to contact was removed from the database. Permission was sought from all patients (or their next of kin if deceased) to access their records.

<u>Bereaved Families</u>

The inclusion of deceased patients was, if possible, important for the integrity of the project. An individual, case by case approach was taken when contacting the next of kin (NOK) of a deceased young person. The healthcare professional identified to have a working relationship with the NOK was contacted, and a personalised letter was sent if it was thought appropriate to do so.

Data Collection

Upon receipt of all relevant permissions, the Project Support Manager interrogated primary care and hospital records to extract information relating to:

- Symptom presentation and consultation frequency in primary care
- Source of referral and point of entry to secondary care for the symptoms that led to a cancer diagnosis
- Evidence of prior contact with secondary care (e.g. outpatient and A&E services) before the episode resulting in the diagnosis
- Time to start of treatment

Analysis

The data was used to construct individual pathway maps for each young person, showing the transition between primary and secondary care displayed on a timeline. All individual route maps were reviewed by a clinical panel comprising expertise from primary and secondary care.

Results

Lymphoma was the most common diagnosis (28%). The other diagnostic groups were carcinoma (20%), germ cell tumour (10%), leukaemia (17%), brain/CNS (7%), bone sarcoma (7%), soft tissue sarcoma (6%), malignant melanoma (5%) and other (1%). Brain/CNS tumours were under-represented and in part reflect low patient numbers observed in the region during the recruitment period. Leukaemia patients were over-represented, which likely reflects duration of treatment.

Route to Diagnosis

93% of TYA had contact with primary care in the period prior to diagnosis. First presentation relating to the cancer diagnosis was to primary care in 89% of evaluable pathways, compared to 7% presenting to A&E and 4% presenting to other healthcare professionals.

The panel evaluated whether cancer was suspected at first presentation. Of those presenting to primary care, cancer was suspected in 34% of cases. This varied by diagnostic group with evidence of cancer suspicion highest in germ cell tumours (i.e. young adults presenting with testicular symptoms) at 67%. Cancer was not suspected at first presentation in any of the bone sarcoma patients.

45% of patients were referred via Two Week Wait (TWW) pathways, 38% presented as an emergency, 11% via GP referrals, 6% other outpatient routes and 1 patient was detected via screening. Of the patients presenting via an emergency route 34% were deemed ‘potentially avoidable’ (i.e. that the referral could have been made earlier) and 66% ‘unavoidable’. Route to diagnosis varied by diagnostic group. All malignant melanoma patients were referred via TWW, compared to only one of the bone sarcoma patients and none of the brain tumour patients.

Key Event Interval Analysis

The longest median diagnostic interval (from first presentation relating to the cancer diagnosis to date of diagnosis) was observed in bone sarcoma patients (81 days, range 24 -140 days). The shortest diagnostic intervals were observed in leukaemia patients, followed by germ cell tumour patients.

<u>Clinical Bottom Line</u>

Of the 98 evaluable pathways, 40% were deemed to represent good or best practice. 44% of pathways were evaluated as requiring room for improvement, 16% of pathways were considered less than satisfactory. This varied between diagnostic groups. All bone tumour pathways were deemed either room for improvement (29%) or less than satisfactory (71%). Of the lymphoma pathways evaluated, 65% were room for improvement and 12% less than satisfactory. In comparison, 78% of leukaemia pathways were deemed to represent good practice followed by 67% of germ cell tumour pathways.

Impact and Benefits

Emerging themes for areas of improvement have been identified including:

- Accountability for/effective management of patients within secondary care pathways
- Radiology reporting and response to positive investigations
- Application of NICE referral guidance in TYA
- Patient experience and role of a debriefing exercise and early re-engagement with primary care

Outcome

The findings will be used to recommend and implement specific local interventions. This will follow further planned interrogation of secondary care pathways e.g. the lymphoma pathway. A project involving early re-engagement with primary care is in the pilot phase.

11. BEST PRACTICE

There have been a number of significant areas of best practice from across the South West TYA Cancer service.

- Most notably is the developing and increasing networked TYA specialist nurse team. Following the successful bid to Teenage Cancer Trust it is expected that by summer 2017 eight posts will be in place offering bespoke care and support to TYA's and their networkers.
- 2016 has also seen the re-establishment of all the designated hospitals steering group meetings supported by a Regional TYA Service coordinator and Project Manager.

The TYA service have developed a data collection tool to record type and level of interventions, enabling the reporting of the scope and impact of the TYA specialist nurse role. It is anticipated that this data tool will be used to guide the Teenage cancer Trust in implementing an outcome measures strategy to support their 'roll out' strategy nationally.

The TYA MDaT is still unique on how TYA MDT's are arranged and managed nationally. Following the successful pilot of the IAM Portal that includes SWIMMS, it is anticipated that the MDaT will be promoted as best practice for age appropriate MDT's.

IAM Portal project (see section 10.1)

Wellbeing initiative (see section 10.2)

'Too Young to Get Cancer?'; National ACE programme project (see section 10.3)

12. SERVICE FEEDBACK

12.1 CQC report December 2016

The CQC recently rated University Hospitals Bristol NHS Foundation Trust as ‘Outstanding’ – an achievement all the more remarkable for the fact that their rating for the Trust moved from ‘Requires Improvement’ to ‘Outstanding’ between two inspections and in only two years – the first Trust in the country ever to achieve such a leap.

The inspectors identified a number of areas of outstanding practice, amongst these the TYA service was highlighted to have;

“continually developed the service, and sought funding and support from charities and organisations, in order to make demonstrable improvements to the quality of the service and to the lives of patients diagnosed with cancer”

12.2. NHS England Chief Executive Simon Stevens said:

“The Teenage and Young Adult Cancer Services at University Hospitals Bristol is such an impressive service - with staff clearly dedicated not only to providing the highest quality clinical treatment for young patients, but caring for their emotional, social and practical needs.

“The Teenage Cancer Trust’s multi-disciplinary; whole-person approach is a great example for other services.”

12.3. UHBristol Recognising Success Awards

Area 61 Teenage and Young Adult team were awarded a ‘Highly Commended’ award at the UHBristol Recognising success awards in the category Clinical team of the Year.

‘The unit is highly regarded across the Trust in leading the way in the delivery of care for young people – quite an achievement in a relatively short period of time.’

13. OBJECTIVES FOR 2017

The overarching objective for 2017 is to consolidate and maintain the model of care evolved to date whilst maintaining a strong focus on innovation and service improvement.

Specific key targets for achievement include

- **Objective 1:** Secure funding for:
    - additional Clinical Psychology resource
    - TYA Advanced Nurse Practitioner
    - Wellbeing Co-ordinator (to continue this post at the end of the Macmillan pilot funding in May 2017

- **Objective 2:** Deliver further developments in the IAM Portal Project across TYA SW and prepare for a pilot evaluation in the East Midlands TYA service. These developments include:
    - the development and evaluation of an IAM 'app'
    - the final design, build and introduction of a TYA MDaT Patient Management system
    - the further development of content within the TYA Help! website

- **Objective 3:** Implement and operationalize the TYA Specialist nursing resource from Teenage Cancer Trust both at the PTC in Bristol and across the TYA SW network

- **Objective 4:** Strengthen medical engagement in the network by ensuring that staff from the principal referring MDT's have time to engage with the TYA MDaT on a consistent basis

- **Objective 5:** Develop a strategy to incrementally improve access to clinical trials.

- **Objective 6:** Publish and disseminate findings from all service improvement initiatives

- **Objective 7:** Improve access to service activity and governance data

- **Objective 8:** Illustrate and map out TYA pathways across the region (including supra-regional pathways)

- **Objective 9:** Benchmark fertility preservation provision across in the South West

- **Objective 10:** Map palliative/hospice care provision in the South West for TYA patients

- **Objective 11:** Consolidate the learning from the ACE project and determine the next steps for intervention development to improve the pathway to diagnosis of TYA’s across the South West