

ANNUAL REPORT

TEENAGE AND YOUNG ADULT SOUTH WEST

CANCER SERVICE

January – December 2018



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Definitions

Bristol Haematology & Oncology Centre	BHOC	Principle Treatment Centre	PTC
Bristol Royal Hospital for Children	BRHC	Site Specific	SiSp
Clinical Nurse Specialist	CNS	South West	SW
Psychology Health Services	PHS	SW Integrated Multi-disciplinary Management System	SWIMMS
Integrated Assessment Map	IAM	Teenage & Young Adult	TYA
Multi-Disciplinary advisory Team	MDaT	University Hospitals Bristol NHS Foundation Trust	UHB
Multi-Disciplinary Team	MDT	Young People	YP
Advanced Clinical Practitioner	ACP		

1. Summary

1.1 Key Achievements

- The Teenage & Young Adult (TYA) service across the South West (SW) have **'REACHED' 94%** of all Young People (YP) captured on the cancer registry diagnosed between 16 and 24yrs of age.
- Continued capital and support from, and close collaboration with, Teenage Cancer Trust and local charities to further develop resources and environments in the designated hospitals within the TYA SW network.
- The SW TYA MDaT is now promoted as best practice for age appropriate MDT's within the IAM Portal the digital platform of choice for Teenage and Young Adult cancer services across the UK.
- In line with the service objectives for 2017, the service has consolidated and maintained the networked model of care. This has been supplemented through the increase of the TYA Clinical Nurse Specialist (CNS) workforce through the adoption of the Germ Cell and Sarcoma CNS by Teenage Cancer Trust based at University Hospitals Bristol NHS Foundation Trust (UHB).
- The regional service has actively promoted peer and social activities for YP both at the Principal Treatment Centre (PTC) and in each of the designated hospitals. Such regular engagement with YP in a programme of activities built around social events promotes and fosters peer support. ([see section 11.3](#))
- Reiki therapy and music therapy were added to the complementary therapy on offer in UHB. All complementary therapies including Reflexology and Indian Head Massage are now funded by local charity [The Grand Appeal](#) and are available for children, teenagers, young adults and their networkers.
- The Teenage Cancer Trust CNS team across the SW won a [British Journal of Nursing \(BJN\) award](#) for innovation. This award recognised the development of the specialist team across the SW through the delivery of expert TYA care along with the development and implementation of the IAM Portal.
- The TYA service featured in a BBC Horizon documentary following the stories of eleven young people with cancer to see how they have dealt with their cancer experience, from diagnosis through to treatment and beyond. [Teenagers vs Cancer: A User's Guide](#) hears from YP directly, in their own words, about their experiences, their thoughts and advice, and their hopes
- The service appointed a TYA Advanced Clinical Practitioner (ACP) for the Teenage Cancer Trust Unit Area 61 in Bristol with funding provided by Jazz Pharmaceuticals and Macmillan Cancer Support.

1.2 Key Challenges

- **TYA pathways** – there are various pathways for TYA patients across the region dependant on age and treatment location. Work continues in order to ensure shared engagement in the development of pathways, service standards, and development initiatives.
- **Transition** – age criteria for admission to paediatric services differ across the network placing significant challenges for transition and management of patients aged 16-17yrs. Work to address this continues locally at each designated hospital and regionally for patients newly diagnosed, still on treatment, and in disease surveillance within this age group.
- **Clinical trials** - there remains 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.
- **Commissioning** - 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. NHS England, through its Children and Young Adult Cancer Services Clinical Reference Group (CYA CRG), has been working on a national service review which aims to deliver the recommendations set out within the Cancer Taskforce report and drive improvements in clinical outcomes and service experience for patients. The review will include a significant focus on the designation of, and relationship between PTCs and Designated Hospitals, as was recommended within the Cancer Taskforce report. The SW TYA service has actively contributed to this review which is expected to be finalised in spring 2019.

2. Service Description

2.1 Population Served

UHB (working in partnership with North Bristol NHS Trust) has been the designated PTC for TYA with cancer in the 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 YP diagnosed with cancer.

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 YP 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 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 offering TYA services across the SW.

They are:

1. [Gloucestershire NHS Foundation NHS Trust](#)
2. [Royal United Hospitals Bath NHS Foundation Trust](#)
3. [Taunton & Somerset NHS Foundation Trust](#)
4. [Royal Devon & Exeter NHS Foundation Trust](#)
5. [Plymouth Hospitals NHS Trust](#)
6. [Royal Cornwall Hospitals NHS Trust](#)

The rationale for this decision was to ensure that all YP were able, whenever possible and appropriate, to access treatment locally.

In order to support this arrangement, all patients were offered access to a dedicated Teenage Cancer Trust CNS (partnership funding between the NHS and Teenage Cancer Trust), a CLIC Sargent social worker, and a TYA Lead Clinician in each of the designated hospitals.

2.3 Aim Of The Service

The aim of the service is to ensure that the care of TYA patients across the SW is of the highest quality, particularly; age appropriate facilities, compliant with the NICE Children's and Young People with Cancer Improving Outcomes Guidance, promotes peer support, provides appropriate facilities, supports transition, provides leadership to the SW as the PTC and constantly strives to improve care through ongoing audit, service improvement and research.

2.4 Objectives Of The Service

- To comply with the standards in the NICE Children's and Young People with Cancer Improving Outcomes Guidance
- To provide support and advice to the teams caring for the TYA patient on all aspects of TYA care including aftercare, in particular through the TYA Multi-Disciplinary advisory Team (MDaT) meeting and liaison with members of the TYA team
- To provide direct patient and family support through the multi-agency resources provided by the TYA MDaT
- To encourage entry to clinical trials through support of patients, increased awareness of location of suitable trials and increased trial availability locally and nationally.
- To enable peer support for TYA patients through events managed by the Youth Support Co-ordinator and the wider regional TYA cancer service.
- To ensure that all patients in UHB and across the region are offered age-appropriate facilities
- To ensure that all staff caring for TYA patients have access to TYA specific education.
- To promote, actively lead and participate in TYA research & quality innovation
- To engage users in the development of the TYA service, including the use of co-creation methodology.
- To evaluate and audit our work
- To ensure that we follow the principals of and are compliant with information governance standards

2.5 Facilities

There are two areas for the care of YP with cancer in the PTC at UHB; Apollo 35 in the Bristol Royal Hospital for Children (BRHC), and Area 61, a purpose built TYA Unit for YP in the Bristol Haematology & Oncology Centre (BHOC).

Apollo 35, caring for YP aged 11-16, is a 14-bedded ward consisting of ten single en-suite bedrooms and a four-bedded bay. Four beds in Apollo 35 directly support YP with cancer. There is active collaboration between Apollo 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 YP with cancer aged from 16 to 24 years. 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, a kitchen and dining space, quiet room, treatment room, and a wellbeing room. The other floor is for day patients featuring three treatment 'pods'; three consulting rooms; waiting area and a staff office.

Images 1 & 2: TYA Unit Area 61 in BHOC



Images 3 & 4: Apollo 35 in BRHC



Age specific facilities have been/are being established now in all of the designated network hospitals, (Figure 1) with support from Teenage Cancer Trust support and other local charities.

Figure 1.

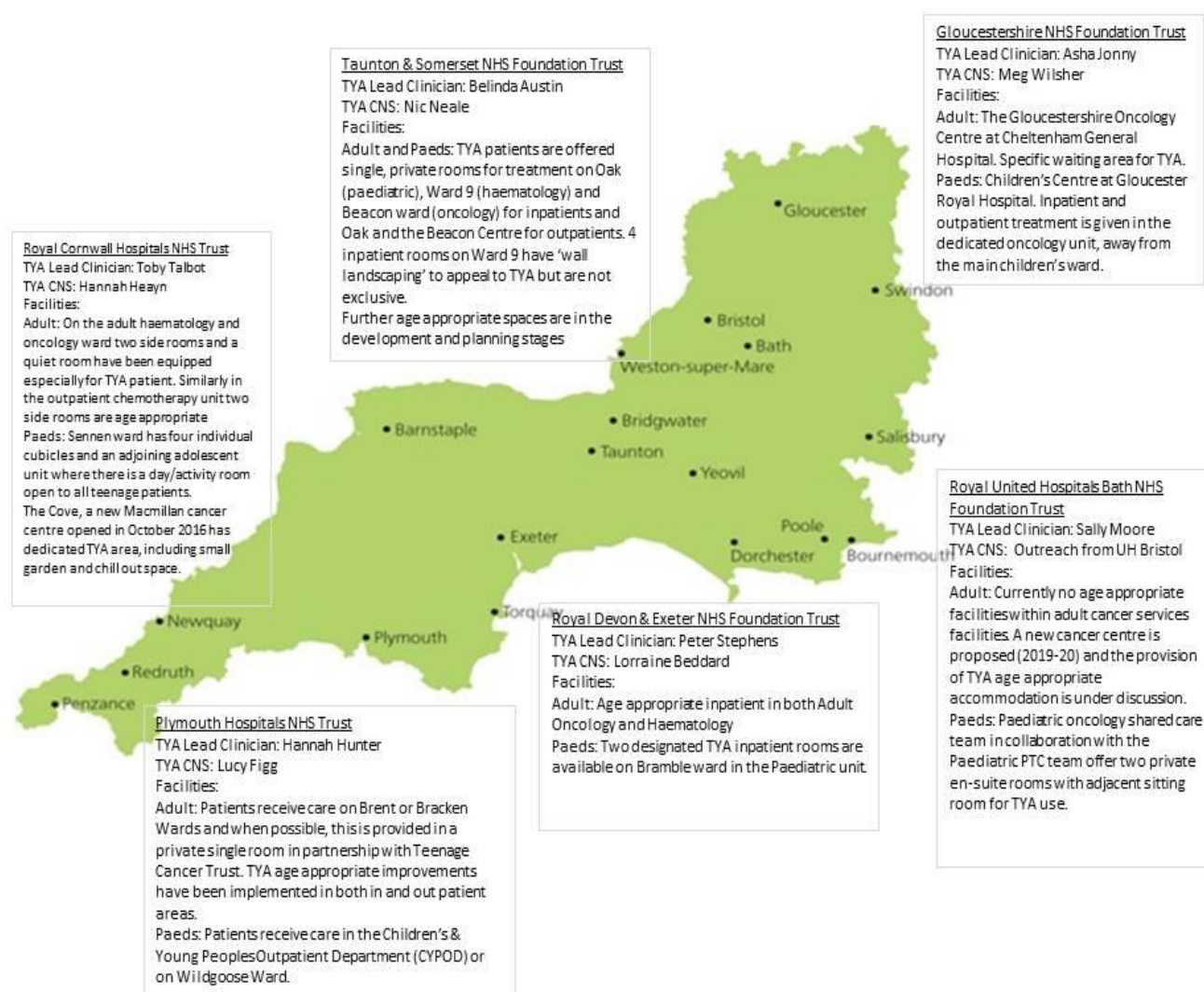


Image 5: Age appropriate accommodation in Royal Devon and Exeter NHS Foundation Trust

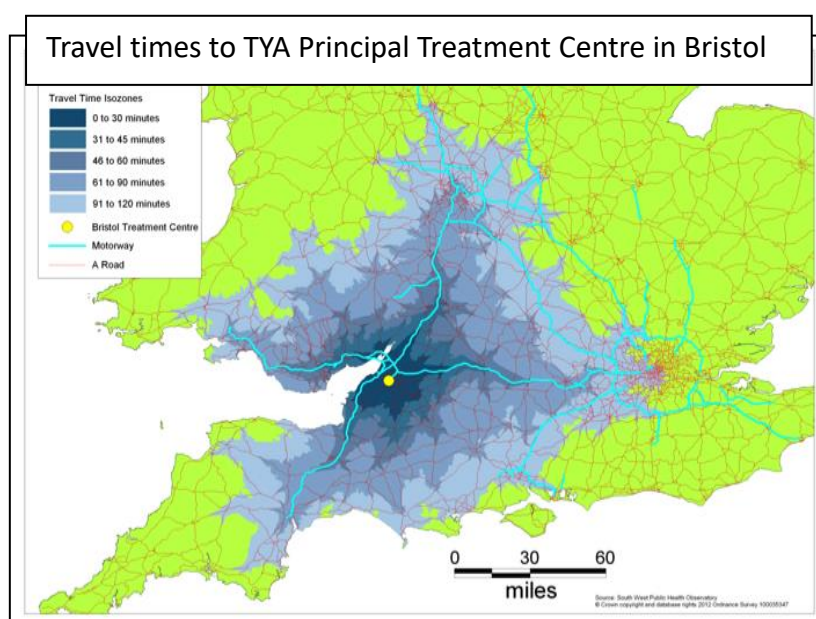


2.6 The Network Model Of Care

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 2) and partly because it was felt that it should be possible to deliver high quality care for many YP using the resources and skills available at the designated hospitals, closer to their home, with the support of the PTC.

Figure 2. 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)



In order to achieve this, the specialised commissioners and Teenage Cancer Trust invested in a number of posts linked both to the PTC and to the designated hospitals.

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”.

2.7 The Role Of The TYA MDaT

National policy (NICE Improving Outcomes Guidance 2005 and the national service specification for TYA cancer) require that all TYA patients (aged 16-24 years) are discussed both at a relevant Site Specific (SiSp) diagnosis and treatment MDT and by the regional TYA MDT. This forms part of TYA Cancer Peer Review Measures/Quality Surveillance. The services provided by the TYA team differ from those provided by SiSp. The SiSp has primary responsibility for the investigation, diagnosis and treatment of cancer and every young person will be formally discussed at the relevant SiSp diagnostic MDT.

We call the TYA MDT the 'MDaT' both to avoid confusion between the two MDTs involved and to emphasise its role as an advisory body. The focus of the discussion at the MDaT is to ensure that each young person's needs are discussed holistically and that the advice and resources of the TYA service are offered to add value to the care each young person receives

The MDaT now also links with the development of the TYA IAM Portal so that YP can assess their needs and gain targeted support and information face to face or online (Image 6 & 7). Patients are encouraged to submit an assessment of their needs to the professionals caring for them, thus forming the structure around which the discussions that take place within 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.

The TYA MDaT is now promoted as best practice for age appropriate MDT's within the IAM Portal, promoted as the digital platform of choice for TYA cancer services across the UK. Following the successful implementation of the IAM Portal in three other services across England (East Midlands, Merseyside/Clatterbridge and South Yorkshire) the TYA team have welcomed staff from other TYA services to learn from this approach. These have included colleagues from The Royal Marsden & Brighton, Northern Ireland, Southampton, UCLH, Cambridge, Newcastle, Scotland, and Wales.

Images 6 & 7: A YP using the IAM Portal to identify both met and unmet needs in partnership with a Teenage Cancer Trust CNS



3. Staffing

Staffing for the TYA SW service consists of those who work at the 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 represents 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 31.12.2018	Full/Part time (wte)	Funded by
TYA Core Team			
Lead Clinician	Dr Rachel Dommett	1.0wte (0.2wte specific to TYA)	NHS
Teenage Cancer Trust Nurse Consultant	Jamie Cargill	Band 8b 1.0wte	Teenage Cancer Trust
Clinical Psychologist	Dr Laura Baker ¹	Band 8a 1.0wte (0.4wte TYA)	NHS
Clinical Psychologist	Dr Mia Foxall replaced Dr Rachel Irwin ²	Band 7 1.0wte (0.4wte TYA)	NHS
Social Worker	Anna Regan replaced Suzie Holmes ³	Band 7 1.0wte	CLIC Sargent
Teenage Cancer Trust CNS	Jax Hulbert	Band 7 1.0wte	NHS
Teenage Cancer Trust CNS	Claire Lewis-Norman	Band 7 1.0wte	Teenage Cancer Trust
Teenage Cancer Trust CNS	Liz Allison	Band 7 1.0wte	NHS
Youth Support Coordinator	Hannah Lind	Band 5 1.0wte	Teenage Cancer Trust
Regional TYA Service Coordinator and Project Manager	Rob Spate	Band 5 1.0wte	Teenage Cancer Trust
MDaT coordinator	Andrea Majai	Band 4 1.0wte (0.5wte TYA)	NHS
Clinicians with designated responsibilities to the TYA service			
Adult Haematology	Dr Caroline Besley	2.0 PA	NHS
Adult Sarcoma	Dr Adam Dangoor	0.5 PA	NHS
Adult Central Nervous System	Dr Alison Cameron	0.5 PA	NHS
Adult Germ Cell	Dr Jeremy Braybrooke	0.5 PA	NHS
Paediatric Oncology	Dr Antony NG	0.5 PA	NHS
Palliative Care	Dr Rachel McCoubrie ⁴	No	NA

Non-core staff at PTC TYA service			
Macmillan TYA ACP	Tamsin Mauri	1.0wte (fixed term project 3yrs)	Jazz pharmaceuticals and Macmillan
Music Therapist	Claire Fraser-Tytler	0.2wte	The Grand Appeal (Local charity)
Reiki Therapist	Raina Nahar	0.4wte	The Grand Appeal (Local charity)
Reflexologist and Indian Head Massage	Clare Greateorex	0.4wte	The Grand Appeal (Local charity)

Notes:

1. Dr Laura Baker has responsibilities to TYA and paediatric oncology and haematology services. Sue Dolby, Consultant Clinical Psychologist and Head of Psychological Health Services at UHB has oversight responsibilities for the psychological support offered to the TYA service. In addition, she receives funding from Teenage Cancer Trust (0.1wte) to support the continued implementation of the IAM Portal Project nationally
2. Dr Rachel Irwin has taken up a secondment and Dr Mia Foxall replaced her in November 2018. She works across adult cancer services including TYA
3. Suzie Holmes went on maternity leave on 31st August 2018 and was replaced by Anna Regan
4. There is no designated session for TYA within adult palliative care, although there is intention to address this in 2019.

3.2 At Designated TYA Hospitals Across The TYA SW Network

All the CNS posts at the designated hospitals are funded in partnership with the NHS and 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			
Teenage Cancer Trust CNS	Megan Wilsher ¹	1.0wte	NHS & Cobalt ¹ Teenage Cancer Trust Adopted
TYA Lead Clinician	Dr Asha Johny	No designated session in job plan ²	NHS
Young Persons Social Worker	See note below ³	-	CLIC Sargent
Royal United Hospital NHS Foundation Trust			
Teenage Cancer Trust CNS	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			
Teenage Cancer Trust CNS	Nicola Neale ⁵	1.0wte	Teenage Cancer Trust/NHS
TYA Lead Clinician	Dr Belinda Austin	No designated session in job plan ²	NHS
Community Worker ⁶	Daniel Honey	1.0wte	CLIC Sargent
Young Persons Social Worker	See note below ⁶	-	CLIC Sargent
Royal Devon and Exeter NHS Foundation Trust			
Teenage Cancer Trust CNS	Lorraine Beddard	1.0wte	NHS/Teenage Cancer Trust
TYA Lead Clinician	Dr Peter Stephens	1.0PA	NHS
Community Worker ⁶	Daniel Honey	1.0wte	CLIC Sargent
Young Persons Social Worker	Richard Nobes	1.0wte shared with Plymouth and Cornwall	CLIC Sargent
Plymouth Hospitals NHS Trust			
Teenage Cancer Trust CNS	Lucy Figg ⁷	1.0wte	Teenage Cancer Trust
TYA Lead Clinician	Dr Hannah Hunter	No designated session in job plan ²	NHS
Young Persons Social Worker	Richard Nobes	1.0wte shared with Exeter & Cornwall	CLIC Sargent

Royal Cornwall Hospitals NHS Trust			
Teenage Cancer Trust CNS	Hannah Heayn ⁸	0.5wte	NHS
TYA Lead Clinician	Dr Toby Talbot	No designated session in job plan ²	NHS
Young Persons Social Worker	Richard Nobes	1.0 wte shared with Exeter & Plymouth	CLIC Sargent
Clinical Psychologist	Dr Louise Brown	1.0wte (0.2 dedicated to TYA)	Macmillan and NHS Trust

Notes:

1. Megan Willsher has a full time post funded jointly and equally by the NHS and a local charity (Cobalt).
2. Only one of the clinical leads for TYA at the designated hospitals (RD&E) has 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 Persons social worker based in Gloucester. Support is now provided by Anna Regan who works as part of the PTC team in Bristol but equity in service access is not assured.
4. Prior to 2017 the workload at the PTC precluded Jax Hulbert's presence on site in Royal United Hospital NHS Foundation Trust & North Bristol NHS Trust on a routine basis. The successful bid submitted to Teenage Cancer Trust and consequent appointment of an additional CNS post (1.0wte) has addressed this deficit.
5. Nicola is based in Taunton but covers Somerset including Yeovil District Hospital which is a non-designated TYA hospital.
6. There is no CLIC Sargent young person's social worker based in Taunton. Support for patients in Somerset may be allocated to Anna Regan who works as part of the PTC team in Bristol, or to Richard Nobes, CLIC Sargent social worker in Exeter and Plymouth. Dan Honey CLIC Sargent young person's community worker offers support alongside initial signposting to an appropriate social worker when required.
7. Kerry McKay left her role as Teenage Cancer Trust CNS in November 2018 and was seconded as full time Lead Haematology CNS and Myeloma Lead. Lucy Figg was subsequently seconded as full time Teenage Cancer Trust CNS covering Plymouth and South Devon.
8. Hannah Heayn went on maternity leave in June 2017 with her post covered by Nicola Clapson. Nicola returned to her role as a palliative care CNS.

4. Clinical Activity

Cancer registration data suggest that approximately 150 TYA patients are diagnosed each year across the SW. Over the last few years there has been a steady estimated increase in patients supported by the TYA service (2015=66%; 2016=87%) with the aim to reach 100% of TYAs diagnosed in the SW. However there was no accurate measure on how many TYAs have been referred to the service and accessed support. In 2017 we undertook an audit to determine what proportion of TYA aged between 16yrs and 24yrs diagnosed (new or relapsed) with cancer had been 'reached' by the service. This audit is now repeated twice a year.

The overall reach rate for 2018 = 94%

4.1 Diagnosis Classification Of Patients Discussed At TYA SW MDaT In 2018

263 patients were discussed at the MDaT in 2018. Of these, 138 were new to the MDaT, of whom 125 were newly diagnosed (i.e. 'new to cancer').

Table 3: Diagnostic classification of new patients discussed by MDaT in 2018 using updated Birch classification

BIRCH CLASSIFICATION ANALYSIS				
Group			All	New to MDaT & Cancer
1	Leukaemia			
	1.1	Acute lymphoid leukaemia (ALL)	7	5
	1.2	Acute myeloid leukaemia (AML)	3	2
	1.3	Chronic myeloid leukaemia (CML)	1	1
	1.4	Other & unspecified leukaemia	1	1
2	Lymphoma			
	2.1	Non-Hodgkin lymphoma (NHL)	2	2
	2.1.1	Non-Hodgkin lymphoma, specified subtype	5	5
	2.2	Hodgkin's lymphoma (HL)	6	6
	2.2.1	Hodgkin lymphoma, specified subtype	8	8
	2.2.2	Hodgkin lymphoma, subtype not specified	14	12
3	CNS tumours			
	3.1	Astrocytoma	1	1
	3.1.3	Glioblastoma and anaplastic astrocytoma	1	1
	3.2.1	Oligodendroglioma	2	2
	3.2.2	Other specified glioma	1	1
	3.2.3	Glioma NOS	3	3
	3.4.1	Medulloblastoma	1	
	3.6	Unspecified intracranial & intraspinal neoplasms tumours	1	1
4	Bone tumours			
	4.1	Osteosarcoma	3	2
5	Soft Tissue Sarcoma			
	5.2	Rhabdomyosarcoma	2	2
	5.3	Other specified	3	2

	5.3.1	Liposarcoma	1	1
	5.3.3	Synovial sarcoma	1	1
6	Germ Cell			
	6.1	Gonadal germ cell & trophoblastic neoplasms	19	19
	6.2	Germ cell & trophoblastic neoplasms of non-gonadal sites	1	1
	6.2.2	Other non-gonadal germ cell and trophoblastic tumours	1	1
7	Melanoma and Skin Carcinoma			
	7.1	Melanoma	14	12
	7.2	Skin carcinoma	2	2
8	Carcinoma (excluding skin)			
	8.1	Carcinoma of thyroid	7	6
	8.2	Other carcinoma of head and neck	2	2
	8.2.3	Carcinoma of nasal cavity middle ear sinuses larynx and other ill-defined sites in head and neck	2	2
	8.4	Carcinoma of breast	6	5
	8.5	Carcinoma of genito-urinary (GU) tract	1	1
	8.5.3	Carcinoma of Ovary	1	1
	8.5.4	Carcinoma of Cervix	2	2
	8.6	Carcinoma of gastro-intestinal (GI) tract	2	2
	8.6.1	Carcinoma of colon & rectum	1	1
	8.6.3	Liver	1	1
	8.7	Other not classified elsewhere (NEC)	2	2
9	Miscellaneous specified neoplasms NEC			
	9.2	Other rare miscellaneous specified neoplasms	2	2
10	Unspecified Malignant Neoplasms			
11	Non malignant			
	11.1.	Aplastic anaemia	2	2
	11.10	Langerhans Cell Histiocytosis	3	2
TOTALS			138	125

Lymphoma (26%), Carcinoma (20%), Germ Cell Tumours (17%), Leukaemia (7%), Central Nervous System (CNS) tumours (7%) and Sarcoma (bone and soft tissue) (6%), still represent the most frequent major diagnostic groups amongst newly diagnosed patients. There is concern that the criteria of referral for patients with benign or low grade brain tumours are not consistent. A review will be undertaken in 2019 with NBT and Plymouth Neuro-oncology services.

Patients are referred to the TYA MDaT from a wide range of SiSp 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 the new patients discussed at the MDaT in 2018.

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

Table 4: Referring MDT for all patients discussed by MDaT for the first time in 2018 (n=138)

Patient Diagnosis	All		New to cancer	
	No. Pts	%	No. Pts	%
Haematology – including lymphoma and Leukaemia	49	31.5	41	32.5
Unknown	14	10	12	10
Skin	14	10	12	10
Head & Neck including thyroid	12	9	11	9
Germ Cell including Testicular	9	6.5	9	6.5
Urology	8	6	8	6.5
Gynaecology	7	5	7	5.5
Sarcoma	7	5	6	4.5
Central Nervous System /Neuro oncology	7	5	6	4.5
Paediatric	6	4	3	2.5
Breast	4	3	4	3
Colorectal	3	2	3	2.5
Lung	1	1	1	1
Cancer of Unknown Primary	1	1	1	1
Hepatobiliary Pancreatic	1	1	1	1
	138	100	125	100

4.2 Patient Demographics & Completeness Of Data Logged At TYA SW MDaT

Table 5 details the demographic profile of the 138 patients discussed for the first time by the TYA MDaT in 2018 and also provides an assessment of the completeness of data collection.

Table 5: Details of new patients discussed by TYA MDaT

DATA ITEM	No.	%
Patients first discussed in 2018	138	100
Male	70	51
Female	68	49
Ethnicity	138	100
White : (White) British	65	47
Not recorded	53	38.5
Not Known	14	10
White : Any other white background	4	3
Mixed : White and Asian	2	1.5
Age at MDaT Registration	138	100
0 – 15 years	1	1
16 – 18 years	27	19
19 – 24 years	103	75
≥ 25 years	7	5

Cancer Pathway Point at MDaT Registration	138	100
New diagnosis	125	91
Recurrence	7	5
Other	6	4
Hospital centre registered from:	138	100
Bath	5	3.5
Bristol (UHB)	50	36.5
Bristol (NBT)	2	1
Exeter	16	12
Gloucester/Cheltenham	21	15
Plymouth	13	9.5
Taunton	9	6.5
Torbay	1	1
Truro	18	13
Yeovil	1	1
Other	2	1

Clinical Trial Entry	138	100
Yes	10	7
No (non- recruitment)	98	71
Not recorded	30	22
Reason given for non-recruitment	98	100
Suitable trial not available	94	96
Patient eligible but trial not offered	1	1
Patient eligible but declined	1	1
Not eligible	2	2

Fertility preservation recorded	138	100
Treatment not expected to affect fertility	52	37
Achieved Male - Sperm Storage	35	25
Achieved Female - Oocyte Freezing	5	3
Achieved Female - GnRH analogue	4	3
Achieved Female - Ovarian Tissue Freezing	2	3
Insufficient time to achieve fertility preservation before treatment started	13	9
Other	9	7
Patient declined	7	5
Not recorded	11	8

Data collection has continued to improve, however the data suggests that the completeness of data collection in relation to ethnicity, reason for non-recruitment to a clinical trial and fertility preservation could be improved. Furthermore the number of relapse patients is not indicative of actual clinical activity and efforts will be needed to ensure all such recurrences are discussed and recorded at the MDaT. With the introduction of IAM Portal SW Integrated Multi-disciplinary Management System (SWIMMS) data collection and completeness has improved in 2018. This is the responsibility of the Teenage Cancer Trust SW TYA Regional Service Coordinator and Project Manager, and with the implementation of monthly auditing and quality assurance this will continue in 2019.

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 as a TYA specific alternative to the Macmillan eHNA or other SiSp holistic needs assessments in order to better capture information important to the care and support of YP with cancer.

The IAM explores YP'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 YP 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 an 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 three point scale (1-3 or green, amber & red) which indicates the level of concern and/or need for information and support expressed by the YP in each area.

All patients as part of the standard offer are encouraged to complete an IAM both at the start and end of treatment. Of the 125 YP new to cancer and discussed for the first time at MDaT, 95 (76%) had an IAM score recorded at diagnosis. Although our aim is that all YP have an IAM it is evident that it is not appropriate for all when being discussed at the MDaT. Reasons include 1. registration only as patient declined support and 2. patients who are discussed at a pathway point encompassing both diagnosis and end of treatment (e.g. surgery alone). The IAM Portal project team have been asked to add an additional dataset to include this need. Of those finishing treatment, all YP will receive an end of treatment IAM.

Figure 3 below illustrates that of the 95 IAMs completed at time of diagnosis 43% were completed independently by the YP or in partnership with a health care professional, and 57% professionally led. Efforts will continue in 2019 to improve engagement with the IAM Portal at diagnosis.

Figure 3

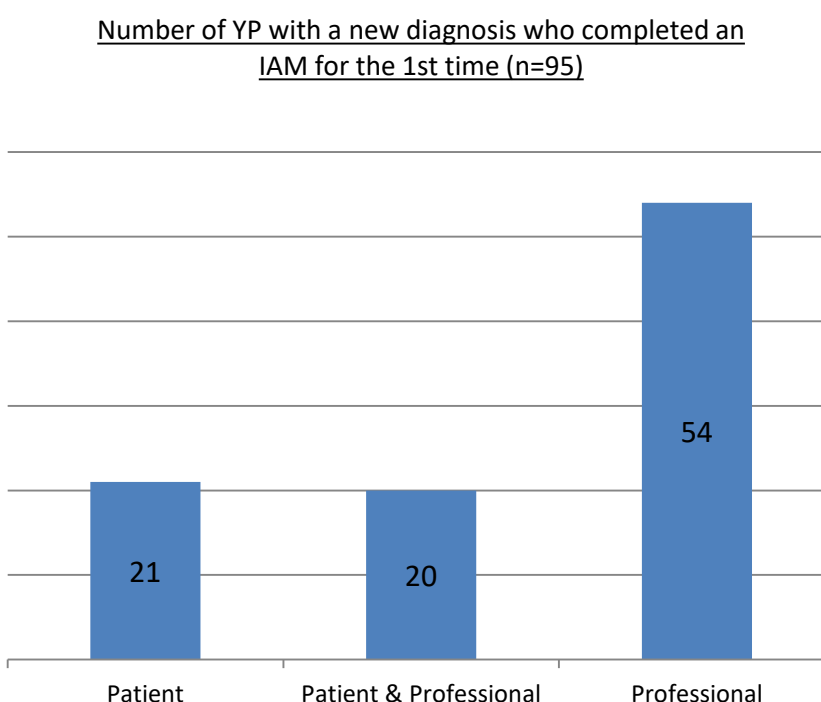
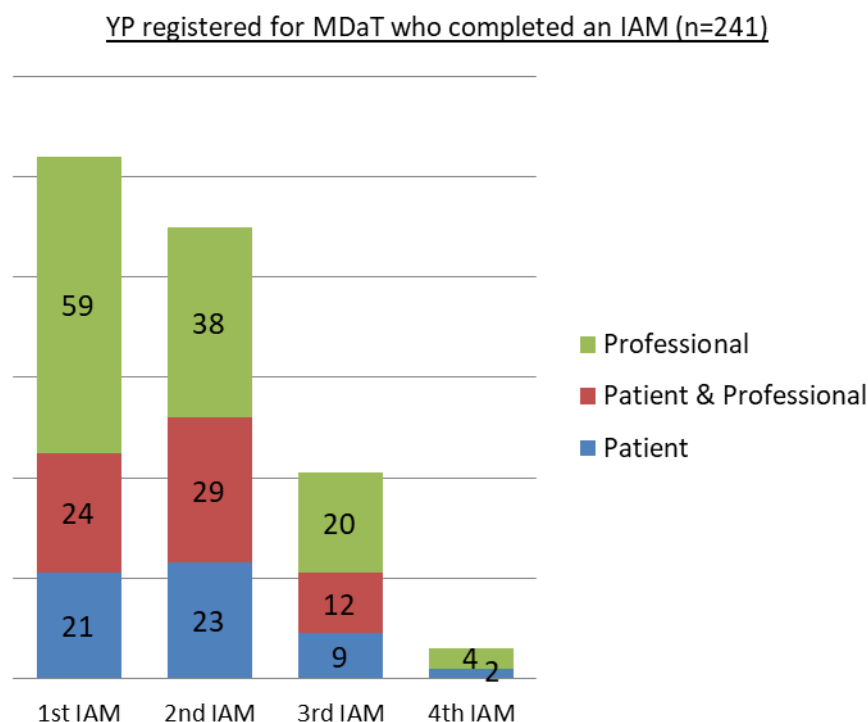


Figure 4 below illustrates that 241 IAMs were completed in 2018 with 55 (22%) completed individually by YP and 65 (27%) completed by a YP and health care professional in partnership.

Figure 4



We continue to encourage and empower YP to complete an IAM independently or in partnership with a health care professional as this will provide us with data and information required to tailor support individually. It is expected that as the 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.

4.4 Clinical Psychology Provision

During the period between January 2018 and December 2018, 64 referrals were accepted for specialist and targeted direct clinical work with TYA's and their networkers. This is an increase of 37% from 2017. 50 referrals were seen as outpatients with 226 follow-up appointments. The average number of follow up sessions was 4.52. (see Table 6 below)

14 TYA's were seen as inpatient referrals with 37 follow-up appointments, an average of 2.6 follow-up sessions. This data excludes some indirect patient-focussed work (e.g. time spent preparing therapeutic resources or preparing reports/referrals to other appropriate services). 24 appointments were not attended or cancelled, which is a reduction of 58%, this could be attributed to both psychologists having a work mobile phone.

Table 6.

Referrals- Outpatients	New	Follow Up	Average Follow Up
276	50	226	4.5
Referrals- Inpatients	New	Follow Up	Average Follow Up
51	14	37	2.6
Overall Total	New	Follow Up	Average Follow Up
327	64	263	5.1

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

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 SiSp MDT caring for TYA. This included attendance at the weekly TYA MDaT meeting, a monthly reflective practice for the TYA team, a monthly clinical supervision group for cancer support workers, a monthly CNS clinical supervision and individual 1:1 clinical supervision of the TYA reiki therapist, reflexologist and music therapist. Additional psychological consultation and supervision regularly took place with other MDT members as required. Psychology Health Services (PHS) took 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.

PHS has had continued involvement in the development of the IAM Portal which includes access to supported self-management to build emotional resilience and psychological wellbeing. The PHS supported the TYA patient experience survey for both patients and networkers in line with quality surveillance. PHS has contributed to teaching including Strictly TYA, Penny Brohn training day and UWE training module.

Psychology continued to support the development of the living well course in partnership with Penny Brohn and is in the process of undertaking a review of the content and putting a training package together for Penny Brohn staff.

The 8a Clinical Psychologist took over as co-chair of the national TYA psychology network. Additionally she had two clinical psychologists in training on six month placements and led on the development of a TYA specific palliative and bereavement pathway for the Bristol TYA service to be completed in 2019. The 8a Psychologist supervised a small scale research project investigating 'Chronic Fatigue in Teenage and Young Adult Cancer'. The study involves asking staff about their knowledge and management of chronic fatigue in teenagers and young adults with cancer, it will be completed in 2019.

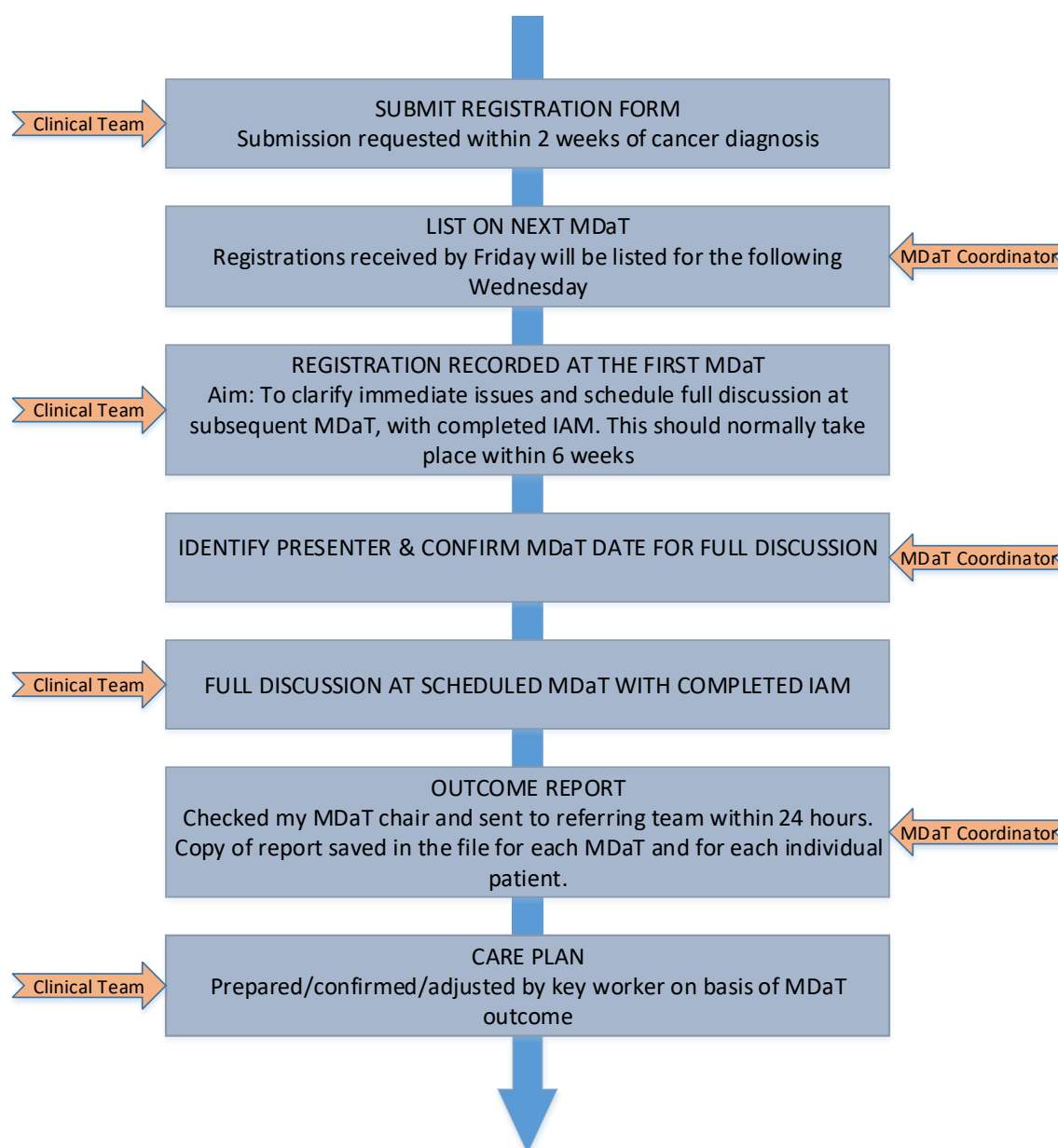
Objectives for psychology provision in 2019-20 include continuing to contribute to service developments, research and audit. We will evaluate and disseminate outcomes from the end of treatment clinic. The 8a Clinical Psychologist will continue as co-chair of the national TYA psychology network. This year two Clinical Psychologist in training placements have been assigned to the 8a Clinical Psychologist. In 2019 the 8a Clinical Psychologist is supervising a research project with two Masters in health psychology students; the project is title "'Parental experiences of their children's fatigue, pain & mood in teens with cancer'. The outcomes are hoped to inform the service and improve resources we provide with a parent voice. The 8a psychologist will also be piloting a 'managing certainty group' for TYA's.

5. The TYA MDaT

The TYA MDaT takes place as an online WebEx meeting and is held weekly on Wednesdays from 12:30-14:00. The referral of new patients is managed as a two-step process. Figure 5 summarises the process:

Figure 5

Summary of TYA MDaT Process for new patients from 6th April 2016



First, we ask that patients are registered using SWIMMS using this link: www.swimms.co.uk for online registration or via a registration form by contacting the MDaT Coordinator at UHB. 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 4-6 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 Nurse Consultant or TYA Lead Clinician) 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 submitted prior to the meeting to structure the conversation. If the YP 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.

For more information on the referral process and support offered by the TYA Cancer service please visit our website via [SW TYA Cancer Service information for professionals](#)

Table 7 & 8 shows the attendance by core and non-core members of the TYA MDaT at meetings held during 2018. Target attendance by individual core members of the TYA MDaT is 66%.

Table 7 and Table 8: Attendance by core and non-core members of the TYA MDaT

Attendance of core members of the MDaT according to Peer review	% Meetings Attended
TYA Lead Clinician	83
TYA Nurse Consultant	81
TYA MDaT Coordinator	100
Clinical Psychologist	90
Teenage Cancer Trust CNS (Bristol & Bath)	81
Youth Support Coordinator	79
CLIC Sargent Social Worker (Bristol)	73
Paediatric Consultant	58
Adult haematology Consultant	31
Adult sarcoma Consultant	10
Adult Central Nervous System Consultant	8
Adult germ cell Consultant	0

Attendance of non-core members of the MDaT according to Peer review	% Meetings Attended
Teenage Cancer Trust CNS (Plymouth)	100
Teenage Cancer Trust CNS (Truro)	69
Teenage Cancer Trust CNS (Taunton)	85
Teenage Cancer Trust CNS (Gloucester)	83
Teenage Cancer Trust CNS (Exeter)	83
CLIC Sargent Social Worker (Exeter/Plymouth/Cornwall)	48

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.

Despite illustrating this in 2016 the fact remains that only one of the TYA lead clinicians at the designated hospitals have time adequately identified and available within their job plans to fulfil this role. Whilst the appointment of a network coordinator has supported 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 have been reviewed and reinforced. These meetings serve to keep local hospital trust management informed as well as ensuring a regular interface between the local TYA lead team and the TYA Lead Clinician and Nurse Consultant.

During 2017 the Children and Young People's Cancer Clinical Reference Group (CYP CRG) have undertaken a systematic review of the national specification for the commissioning of cancer services. The measures are not expected to be available for public consultation until spring 2019 with publication later in 2019. The network within the SW will need to consider these recommendations to ensure that the configuration and membership is fit for purpose. Until then the network will continue to meet with support provided by the two cancer alliances in the SW.

7. Quality Surveillance

7.1 Areas Of Non-Compliance

A quality surveillance self-reporting exercise was undertaken in 2018. Table 9 details areas on non-compliance which have been identified in previous years and remain an issue.

Table 9

Non-compliant measure	Update on action to address
Other staffing (AHPs)	Currently a risk within the PTC. Business case submitted annually for investment for dedicated AHPs including physiotherapy, occupational therapy and dietetic support.
MDaT quorum	Clinicians from SiSp Teams within the PTC are funded to attend the MDaT but attendance is not in line with recommendations.
MDaT attendance	As above

8. Patient Experience

The annual patient and networker (defined as family, friends and others close to the patient) feedback questionnaires for 2018 were disseminated across the region at the beginning of 2019 and remained open online until March 2019. The questionnaires were available in online and paper formats.

The Teenage Cancer Trust CNS and wider TYA team were crucial to maximising the response rates of these questionnaires and ensuring that feedback was received from across the SW. A full report is available on request.

8.1 TYA Patients Feedback

The number of questionnaires returned was 61

Based on the multiple distribution channels used for the circulation of the questionnaire it is not possible to provide an estimate of the number of questionnaires that were actually distributed. Questionnaires were available in both paper and online versions. Moving forward we would like to standardise our distribution methods across the region for more accurate representation of the service and to allow for calculation of response rates. We would estimate that we had an approximate return rate of 20% based on the number of patients referred to the service in the last 2 years. Thirty-four online questionnaires were completed with twenty-seven paper based questionnaires returned.

Summary

The results showed that patients rated the support provided by the SW TYA cancer service very highly. There was a good representation of surveys returned from across the region, from both male (31%) and female (69%) patients. The questionnaire was completed by an equal number of patients currently receiving treatment and beyond treatment.

Areas with particularly positive feedback were;

- 94% of patients being happy with information provided at transfer or transition of care
- 90% were happy with the support and information provided after treatment finished
- 82% of patients reported treatment options being clearly explained
- 84% of patients said they had a chance to meet somebody from the TYA service

Patient's comments demonstrate positive feedback;

- *"Amazing support"*
- *"A wonderful team and now having a TYA support worker has been fantastic."*
- *"The TYA are great! I couldn't fault them when I needed them and I am still receiving support from them regarding work and ongoing treatment. The TYA meet ups are also really helpful and give you a great chance to meet other young people in your situation."*
- *"Top notch help, they go above & beyond"*
- *"TYA Nursing team care is second to none and very efficient. Hospital team is like a family now. Top notch"*

Most patients said they were offered a holistic needs assessment after diagnosis, but 11% were unsure if they had been offered an IAM. Half of the patients who had used the IAM portal said they would recommend the IAM portal to other young people. Those young people used the portal to find information but also felt that by using it they were listened to as an individual. Additionally patients reported that it helped them 'talk or think about how cancer might affect all areas of my life and to get the support I wanted'.

Patient's feedback about the IAM portal was generally positive;

- *"Good system for staff to see how I'm feeling without me having to say anything to them"*
- *"Good traffic light system to flag up areas that may be of concern"*
- *"It's a good way to express yourself. To let other people know how you are feeling."*

Patients reported their cancer diagnosis affected all areas of wellbeing, including;

- physical wellbeing (93%)
- emotional wellbeing (92%)
- education and work (89%)
- interests and social life (84%)
- general lifestyle (80%)
- impact on relationships (75%)
- financial situation (74%)
- sex, sexuality and fertility (70%)
- housing and finance (51%)

There was a variation in the time point at which patients felt most affected, but during treatment received the greatest number of responses.

Areas which require continued development include the support and information provided after treatment finished and to ensure all treatment options are clearly explained to patients. One patient commented on an unhelpful experience of the transition process. The questionnaire also illustrates a need for continued development and implementation of the IAM portal; this is demonstrated by patient comments which indicate that some did not know its purpose and therefore may not have gained the full benefits of the IAM portal and supported self-management.

8.2 TYA Networkers

The number of questionnaires returned was 23

Based on the multiple distribution channels used for the circulation of the questionnaire it is not possible to provide an estimate of the number of questionnaires that were actually distributed. The distribution methods used were via patients, direct to "networkers", via professionals across the SW. As with the patient questionnaire we would like to standardise our distribution methods across the region. Questionnaires were available in both paper and online versions. 2 online questionnaires were completed with 21 paper based questionnaires returned. The questionnaire was predominately completed by female networkers (87%).

Summary

The results showed that networkers rated the support provided by the SW TYA cancer service very highly. Networkers' provided many positive comments;

- *"TYA have helped in every way they could and we are extremely grateful"*
- *"(staff name) from the hospital for TYA has been very helpful. She advised which claims we could get and helped us get them"*
- *"Emotional support for me and my son from (staff name) was wonderful. She goes above and beyond to help."*
- *"Really don't think we would have got through this without the TYA team. Their personal touch is invaluable"*
- *"All TYA team have been great"*
- *"The TYA team have been truly amazing"*
- *"As a family we have had amazing support from the TYA Team especially (staff name)".*

All networkers surveyed said the information they received was helpful, and two thirds preferred to receive information face to face and provided by a member of the TYA team. Nearly all networkers reported they needed help and support throughout all stages of treatment rather than at one specific time point and emotional support was the primary type of support given. Three quarters said they received enough support to be able to support young people throughout treatment. The area networkers reported needing the most support was emotional support and information about the illness.

However, a quarter of networkers were unsure whether they had received enough support. All networkers stated that they had increased difficulties with their wellbeing as a result of the diagnosis. A diagnosis resulted in increased difficulties in every aspect of daily living. The areas of daily living affected the most were;

- 'spare time'
- 'social life'
- 'financial situation'
- 'wellbeing'

Areas identified for improvements included more liaison between educational establishments and information in regard to available support services i.e. counselling, support groups, hat shops etc.

The information gathered in this questionnaire will be used to inform and identify areas for improvement in the provision of age appropriate care. This survey is distributed annually and reviewed as part of the SW TYA Service so continuous service development and improvements are made across the region.

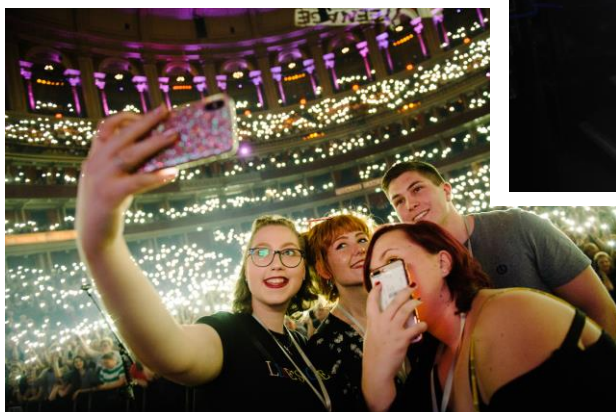
9. Activities And Peer Support

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 120 YP are on her active contact list. She has met most of them, engages regularly with at least 50% 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 and music sessions (every week). Other regular group events are arranged quarterly, for example “Look good feel better” sessions and D.J Workshops; intermittent activities include art workshops and a monthly social/ peer support group which has included meals out, bowling, escape games and comedy gigs

“Our social evening at ‘Stokes Croft china was a very fun, creative evening. Run by the people’s republic of Stokes Croft, the ethos of the organisation is socialism and civil liberty. They are known for creating radical fine English bone china, so we all made a beautiful piece to take away.... But definitely not a cuppa that you would give to your grandma!!!”

Images 8, 9 10, & 11: Art and Craft workshops, River Avon Cruises and Royal Albert Hall



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 particularly useful for inpatients that are bed bound or in isolation or when a young person doesn't have much support from friends or family.

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

"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!"

"She handles everything! From organising trips that help take your mind off of treatment, to popping in for a chat, making sure there are no problems, it's nice to know there's someone on your side. A positive and friendly face to keep everything upbeat, and she always seems like she knows what she's doing with regards to the more complex hospital rules and systems too."

"Hannah has helped lots with the unfortunate circumstances I found myself in not that long ago. By organising so many events just to take our minds off the worst even for a couple of hours and she's a ray of sunshine which makes you feel like it can't be that bad."

9.1 Peer Support Across The Network

There is a recognised need for peer support for TYAs diagnosed with cancer. Yet TYAs receiving treatment locally without a dedicated TYA unit and out-with a PTC such as in Bristol are unlikely to regularly meet any other young people of a similar age.

Recognising this need the TYA service has developed four support groups to offer peer support for patients treated in Cornwall, Plymouth, Exeter and Taunton. The groups meet every 6 weeks and are supported by the staff from the TYA cancer service with partnership funding provided by Teenage Cancer Trust and CLIC Sargent. This programme has been fully evaluated in 2018 and a full report will be available in 2019 ([Please see section 11.3](#)).

32 YP across the SW attended the Teenage Cancer Trust FYSOT weekends (under and over 18yrs), Ellen MacArthur sailing trips, Royal Albert Hall gigs hosted by Teenage Cancer Trust & The Way Forward initiative.

10. Education & Training

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

10.1 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.

Two ‘Strictly TYA’ study days were delivered in March and September in 2018. 32 regionally based multi-professional delegates attended, including delegates from Jessie May, Taunton and Plymouth hospitals. As in 2017 feedback was extremely positive and all either agreed or strongly agreed that they had “learnt a lot from the study day” and all “would recommend to their colleagues”.

- “Please come to Plymouth to talk to more staff and share what we have heard today. This has been a great insight for me and my colleagues but I’m aware we have only scratched the service.”
- “Enjoyed today’s course and content immensely. I feel it is a course to be offered more to HCPs across the country.”
- “Thank you all for your time today and your part in delivering a wonderful informative day – you all do a fantastic job.”

10.2 Other Teaching / Training

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

The team has also facilitated a number of visits from CLIC Sargent, Teenage Cancer Trust and other organisations, who are provided with a guided tour of the TYA Unit and meet members of the team. In particular the TYA Team in Bristol has welcomed 52 members of staff from CLIC Sargent since May 2018. The objectives of the visits were to learn more about the unit and to find out about the particular work that CLIC Sargent does alongside the support provided by the service. All of those who attended felt that these objectives were met and would recommended a visit to others.

Other comments:

- *“I think the visit was a great opportunity to get a more thorough understanding of how important the work the hospital and CLIC Sargent does is, from a different point of view and highlights how important it is to those being treated.”*
- *“Suzie and Jamie were fantastic. I really enjoyed the visit and found it so useful to gain a deeper understanding of the services and work that CS social workers do. I'd strongly recommend all CLIC Sargent office staff to take part”*
- *“I think it was really useful to see what's happening at ward, and what our social workers are offering to service users”*

- *“This experience was invaluable and we absolutely need to be taking more advantage of the fact we have this five minutes from the office.”*
- *“This visit was highly valuable and I could not recommend it higher to my colleagues. It would be good if this could be incorporated into staff inductions somehow. Jamie & Suzie were full of enthusiasm and showed a passion for their work throughout, I managed to gain a far more in depth knowledge than I previously had about the impact of cancer on those that we support.”*
- *“It was really wonderful to see how closely CLIC Sargent and Teenage Cancer Trust work together and good to see what a friendly space there is for the young people and their families on the ward. Being in the fundraising team, it was an important reminder of what we do and who we are supporting.”*

10.3 Conference Presentations & Publications

In September 2018 five members of the team attended the TYAC annual Conference – Contemporary issue in youth health and cancer. Lorraine Beddard (Teenage Cancer Trust CNS RD&E) won 2nd prize for best poster in the Lisa Thaxter awards. The abstract titles were:

- The sophisticated ordinary: An evaluation of regional based teenage and young adult (TYA) peer support groups. Beddard, L, Nobes, R, Baker, L, Spate, R, Irwin, R & Cargill, J
- Place of death audit — investigating preferred place of death against actual place of death for teenagers and young adults (TYA) in the south west of England. Spate, R, Pring, H, Cargill, J, Dommett, R
- The development and evaluation of a reflexology service for adolescents and young adults with cancer and their supporters Greatorex C, Cargill J
- The development and evaluation of a reflexology service for teenagers and young adults (TYA) with cancer and their supporters. Greatorex, C, Hardman, F, Rittenbaugh, C, Spate, R, Cargill, J
- “REACH audit” achieving a service standard of reaching 100% of teenagers and young adults (TYA) in the south west of England who have received a cancer diagnosis. Spate R, Pring H, Dommett R & Cargill J.
- Preparing teenagers and young adults for life beyond cancer – an evaluation of an eHNA facilitated end of treatment clinic. Irwin, R, Allison, E, Hulbert, J, Lewis-Norman, C, Baker, L, Spate, R & Cargill, J
- The IAM portal project: the development and utility of a teenage and young adult specific multi-disciplinary team (MDT) management system in the UK. Cheshire, J, Cargill, J, Beynon, P, Dolby, S, Ross, E, Hennig, A, Harding, A, & Stevens, M.

In December 2018, two members of the SW TYA team attended the 3rd Global Adolescent and Young Adult Cancer Congress – Navigating the road through AYA Cancer in Sydney, Australia giving presentations. . The abstract titles were:

- The IAM portal project: the development and utility of a teenage and young adult specific multi-disciplinary team (MDT) management system in the UK. Cheshire, J, Cargill, J, Beynon, P, Dolby, S, Ross, E, Hennig, A, Harding, A, & Stevens, M.
- Healthcare professional perceptions of online/digital information and support for young people with cancer in the United Kingdom (UK) Lea, S, Martins, A, Morgan, S, Cargill, J, Taylor, R, Fern, L
- The Way Forward programme – Doig, G, Bassett, M, Cargill, J

- The sophisticated ordinary: An evaluation of regional based teenage and young adult (TYA) peer support groups. Beddard, L, Nobes, R, Baker, L, Spate, R, Irwin, R & Cargill, J

Other conferences the team have presented at include:

- 8th Annual Newcastle Upon Tyne Hospitals NHS Foundation Trust Cancer Care Conference, Newcastle, UK
- Florence Nightingale Foundation Annual Conference 2018. Awarded 1st Prize award for best poster – ‘The development and evaluation of a reflexology service for teenagers and young adults (TYA) with cancer and their supporters. Greatorex, C Hardman, F Rittenbaugh, C Spate, R Cargill, J’

10.4 Publications

- Cargill J Professional Boundaries in Adolescent and Young Adult Cancer Care in Olsen P and Smith S (eds) Nursing Adolescents and Young Adults with Cancer, developing knowledge, competence and best practice ref 8684991L, Springer Publications 2018
- Cargill, J Cheshire, J & Stevens, M. Innovating Teenage and Young Adult Cancer Care. National roll-out for award-winning digital app. 20-21 7;4 RCNi Cancer Nursing Practice 2018
- Lea S, Martins A, Morgan S, Cargill J, Taylor R Online information and support needs of young people with cancer: A participatory action research study Adolescent Health, Medicine and Therapeutics 2018;9 121–135
- Stevens M, Beynon P, Cameron A, Cargill J, Cheshire J, Dolby S Understanding and utilising the unmet needs of Teenagers and Young Adults with cancer to determine priorities for service development: the Macmillan On Target programme Vol. 7, No. 6. Journal of Adolescent and Young Adult Oncology 2018

11. Research, Service Development And Audit

11.1 Research

The TYA service has supported two studies as the Principle Investigator.

- ‘Online information and support needs of YP with cancer: A participatory action research study’ – Sponsor UCLH Sarah Lea, Ana Martins, Sue Morgan, **Jamie Cargill**, Rachel M Taylor, Lorna A Fern – **completed September 2018**
- ‘An examination of the role of partners in helping to meet the support needs of adolescents and young adults with cancer’ – sponsor Cardiff university Jane Davies, Jenny Labaton, **Jamie Cargill**, Danny Kelly – **data collection completed September 2018**

Other research activates that the TYA service have contributed to include;

1. James Lind Alliance Priority Setting Partnership - Teenage and Young Adult Cancer: research priorities

The Teenage and Young Adult Cancer Priority Setting Partnership (TYA PSP) was established in 2014 and emerged from the National Cancer Research Institute’s (NCRI) Teenage and Young Adult Health Services Research Subgroup and the Teenagers and Young Adults with Cancer (TYAC) Research and Registration Group, two independent but linked research groups. The research agenda for young people with cancer, broadly those aged 13-24 years at diagnosis, has typically been set by professionals caring for young people with cancer and researchers. Working with the James Lind Alliance (JLA), using an established methodology, the team generated a list of Top 10 research priorities for young people with cancer agreed by multiple stakeholders affected by the disease. Employing rigorous methodology the programme has been able to bring patients, carers/significant others and professionals together to prioritise unanswered research questions in teenage and young adult cancer research. The final report can be found at [James Lind Alliance TYA Cancer: Research Priorities](#).

2. All party parliamentary group on children, teenagers and young adults with cancer

The All Party Parliamentary Group on Children, Teenagers and Young Adults with Cancer (APPG CTYAC) is a cross-party group of MPs and Peers which aims to raise awareness of the issues affecting children, teenagers and young adults with cancer and their families in Parliament. Jamie Cargill, Teenage Cancer Trust Nurse Consultant, was invited to provide evidence at the enquiry alongside CEOs from CLIC Sargent and Teenage Cancer Trust. A copy of the findings can be found at [APPG CTYAC report](#).

11.2 Service Development Initiatives

Strong leadership has been key to the implementation of a network approach of delivering TYA cancer care in the SW of England. Additionally developing a service with a strong emphasis on service development through quality innovation has been essential for success. Current service development initiatives are summarised in table 10.

Table 10

Impact area: local, regional or national	Description of service development / intervention / project
Local	<p>TYA Complementary Therapy Service</p> <p>In 2013 The Macmillan-funded On Target service development project evidenced that TYAs patients and their families wanted access to complementary therapies during their care. To address this need a TYA Reflexology service was piloted in Bristol funded by Teenage Cancer Trust. The pilot was hugely successful and funding was secured to continue the service. The provision of complementary therapies has since been expanded to include Reiki treatments, Indian head massage and music therapy across children and young adult cancer services with funding secured from The Grand Appeal</p>
Local and regional	<p>SACO apartments partnership</p> <p>As a regional centre for TYA cancer care there has always been a requirement to offer accommodation to patients, parents and families who s have to travel from all over the SW to receive treatment in Bristol. With increasing demands the TYA service established a partnership with SACO apartments in 2013. SACO has been offering the use of its Broad Quay serviced apartments, just a short walk from the hospital, free of charge at short notice to families needing accommodation for a brief period of time. Following a review in 2018 this partnership has been extended and contributes to the existing accommodation provided by CLIC Sargent during periods of increased demand.</p>
Local and regional	<p>Age appropriate accommodation</p> <p>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 SW network.</p>
Local and regional	<p>TYA Advance Clinical Practitioner (ACP) project</p> <p>Although ACPs are well-established within cancer care, they are a relatively new introduction in TYA services across the UK. Following funding from Jazz Pharmaceuticals and Macmillan Cancer Support Tamsin Mauri has been appointed as TYA ACP in Bristol. Tamsin will</p>

	undertake an initial scoping exercise to inform the service model design to best meet the needs of all TYA patients being treated in the Bristol Teenage Cancer Trust Unit - see section 11.3 (3)
Local and regional	<p>End of treatment (EOT) clinic/review</p> <p>The TYA cancer service is currently undertaking a year-long pilot of 'End of Treatment Clinic/review' for TYA patients. This is identified as a particularly challenging time for TYA's as they near the end of treatment. This clinic offers a discussion with psychologist and TYA CNS by using the IAM portal and allows for identification of unmet needs. Individuals can then be provided with additional support or signposting for any areas of difficulty. Secondary and primary care are provided with a summary letter along with the patient. To date the feedback has been positive. This initiative is being implemented across the TYA Cancer Network in the SW- see section 11.3</p>
Local and regional	<p>ALL Maintenance project</p> <p>The TYA team working in Bristol identified a need to improve the support provided to TYA patients with acute lymphoblastic leukaemia (ALL) transitioning into the maintenance phase of treatment. TYA patients reported a lack of understanding from other health care professionals, teachers and employers regarding this phase of treatment and how it affects them on a day to day basis. Utilising a co-design methodology we produced clinically accurate, patient led and designed, multi-media films that could be embedded into webpages, social media platforms or shared online. The films are currently being evaluated and will be available for wider use in 2019</p>
Local and regional	<p>Peer support</p> <p>The regional service continues to actively promoted peer and social activities for young people both at the PTC and equally in each of the designated hospitals. A full evaluation of this regional programme has been undertaken during 2018 and a final report will be available soon. Preliminary analysis has demonstrated the significance to both the young people and their networkers alongside the benefit to the health care professionals supporting them. – see section 11.3</p>
Local and regional	<p>Primary care introduction letter</p> <p>The CNS team has implemented an introduction letter to primary care following a young person being diagnosed with cancer. The letter explains what the TYA cancer service does and how it can support young people throughout their cancer diagnosis alongside their treating team.</p>

Local and regional	<p>Prospective data collection – place of death</p> <p>In 2017 the service undertook an audit of the place of death of patients alongside scoping the accessibility and criteria to hospice care for TYAs aged. This data is now collected prospectively as part of the TYA MDaT.</p>
Local and regional	<p>Penny Brohn Living Well Programme for parents/carers of TYA cancer patients</p> <p>Continued partnership between TYA Cancer service with Penny Brohn delivering ‘Living Well’ integrative wellbeing courses for supporter of TYA patients’. Funding initially provided by Simply Health in 2016 to deliver two courses per year the programme is now internally commissioned by Penny Brohn with a further three courses planned for 2019. Feedback has shown that Living Well courses for the supporters of TYA with cancer were very well received and met supporters’ needs and expectations. Data has also shown this might have a secondary impact indirectly for the TYA cancer patients themselves. The project team will continue to collect data on future courses to develop and improve this important service provision. - publication pending</p>
Local, regional and national	<p>IAM Portal project</p> <p>Developed by TYA cancer service based at UHB in partnership with Macmillan and Teenage Cancer Trust, members of the TYA team in the SW contribute to the ongoing development of the IAM Portal. The IAM Portal is made up of three components:</p> <ol style="list-style-type: none"> 1. An electronic TYA holistic needs assessment (HNA): The Integrated Assessment Map (IAM) 2. Online TYA specific information and advice resources 3. The TYA South West Integrated MDT Management System(SWIMMS) <p>This project is now being supported and implemented by Teenage Cancer Trust nationally.</p>

11.3 Audit & Evaluations

In addition to the ongoing REACH and Place of Death audits which are embedded in our service delivery model, the TYA team have undertaken two service evaluations during 2018; 1. An evaluation of regional based teenage and young adult (TYA) peer support groups 'the sophisticated ordinary' and 2. An evaluation of an initiative to prepare teenagers and young adults for life beyond cancer. Furthermore funding was secured to appoint a TYA Advanced Clinical Practitioner within the PTC to undertake a systematic service evaluation.

1. AN EVALUATION OF REGIONAL BASED TEENAGE AND YOUNG ADULT (TYA) PEER SUPPORT GROUPS 'THE SOPHISTICATED ORDINARY'

Introduction

There is a recognised need for peer support for teenagers and young adults (TYAs) diagnosed with cancer. Yet TYAs treatment locally without a dedicated TYA unit and out-with a Principle Treatment Centre are unlikely to regularly meet any other young people of a similar age.

Four support groups were developed to offer peer support for this group of patients in the South West of England. The groups meet every 6 weeks and are supported by the staff from the TYA cancer service with partnership funding provided by Teenage Cancer Trust and CLIC Sargent.

Methodology

Questionnaires were provided to TYAs who attended the peer support groups along with any networkers (partners/husbands/wives/friends/siblings) who attended with them. 6 semi-structured interviews were conducted with TYAs, TYA networkers from across the four centres and with staff from the TYA service.

Preliminary Results

A total of 98 TYAs (age 17-27yrs) have attended 53 TYA Peers support events over an 18 month period. Preliminary results suggest that the provision of peer support groups out with a regional centre is highly valued by TYAs, their networkers and staff. TYAs reported that they felt '*less alone*', helped them to '*stay strong*', make friends, and that the group felt safe and comfortable. It gave a source of constant support, improved confidence and allowed access to their staff from the TYA cancer service such as their TYA CNS and CLIC Sargent Young Person's Social Worker or Community Worker.

Discussion and conclusions

The provision of peer support for TYAs makes a significant difference to TYAs and networkers whilst receiving cancer treatment across a regional TYA service. With the development of regional services for TYAs being highlighted as a priority TYA services will need to utilise resources to ensure such initiatives are prioritised in the future.

2. AN EVALUATION OF AN INITIATIVE TO PREPARE TEENAGERS AND YOUNG ADULTS FOR LIFE BEYOND CANCER

Introduction

End of treatment is an extremely challenging time for people with cancer. The TYA Cancer service in Bristol aims to provide support to maximise the physical and psychological wellbeing of teenagers and young adults (TYAs) as they adjust to life beyond treatment. All TYAs in Bristol are discussed at the end of treatment (EOT) within the TYA multidisciplinary advisory meeting (MDaT) yet support offered at EOT lacked consistency. To address this, a formal EOT clinic was piloted.

Methodology

TYAs that had finished treatment (between 6 weeks to 3 months previously) were invited to attend the EOT clinic. The clinic was run by a Clinical Psychologist and Clinical Nurse Specialist and formulated using the IAM (Integrated Assessment Map), a TYA specific electronic holistic needs assessment. Where areas of need were identified, TYAs were supported to think about self-management, identifying appropriate services they could access. TYAs were asked to fill in an electronic questionnaire following the appointment to provide feedback.

Preliminary results

Early analysis suggests that all TYAs reported finding the clinic helpful or very helpful and the discussion was comprehensive. Despite this none of the TYAs indicated that they would change anything about the way they look after themselves as a result of the appointment.

Discussion

Although all TYAs reported finding the clinic helpful, the added value of the clinic will need to be evaluated on an ongoing basis. The pilot phase will be extended to 12 months with feedback from TYA sought specifically regarding anything that could be improved.

3. TYA ADVANCED CLINICAL PRACTITIONER (ACP) PROJECT

Although Advanced Clinical Practitioners (ACPs) are well-established within cancer care, they are a relatively new introduction in TYA services across the UK. Following funding from Jazz pharmaceuticals and Macmillan Cancer Support Tamsin Mauri has been appointed as TYA ACP in Bristol, initially to conduct a service evaluation project to identify those gaps, but subsequently to work within the inpatient and day unit at the PTC.

NHS England (2018) defines Advanced Clinical Practitioner:

“Advanced clinical practitioners come from a range of professional backgrounds such as nursing, pharmacy, paramedics and occupational therapy. They are healthcare professionals educated to Masters Level in and have developed the skills and knowledge to allow them to take on expanded roles and scope of practice caring for patients. ACPs enhance capacity and capability within multi-professional teams by supporting existing and more established roles. They help to improve clinical continuity, provide more patient-focused care, enhance the multi-professional team and help to provide safe, accessible and high quality care for patients”.

Historically the Bristol TYA unit has not had an allocated ACP; yet the demands on services that interface with the TYA service are considerable, impacting on the level of medical support to the TYA unit. There are a number of factors contributing to this including reduction in junior doctor hours, increasing demand of acute care services and the complexity of a cross speciality service.

The ACP post includes an initial scoping and evaluation of the TYA service. This will entail a systematic collection and analysis of data to identify areas for improvement thus highlighting evidence for the ACP to provide quality service improvement within the new clinical role.

The ACP will integrate into the established TYA team and work alongside the many SiSp teams to carry out extended roles which will include; routine management of the TYA cancer patients, including practical procedures and their admission and assessment. The ACP will act as a highly specialised role model and leader for all members of staff working with TYA cancer patients, and play a major role in the continuous development of the service within the Trust, across the SW service and at a national level.

12. Service Profile

The Teenage Cancer Trust CNS team across the SW won a [British Journal of Nursing \(BJN\) award](#) for innovation. This award recognised the development of the specialist team across the SW through the delivery of expert TYA care along with the development and implementation of the IAM Portal.

Dr Rachel Dommett (TYA Lead Clinician) was invited to represent the south of England on the Children and Young Adult (CYP) Clinical Reference Group (CRG) during 2018. This position is ongoing in 2019 which will ensure the specific needs of the SW service are represented at national level.

Jamie Cargill TYA Lead Nurse was appointed as a Teenage Cancer Trust Nurse Consultant in May 2018. Jamie joins a Teenage Cancer Trust Nurse Consultant Forum advising the charity on service delivery nationally and directly supports the South Central & Wessex and the Welsh TYA Cancer services. Jamie was also appointed Chair of the professional education group of TYAC having been deputy chair since 2014. The main output for this group is the delivery of the TYAC annual conference for professionals working with young people with cancer.

The TYA service was invited by the BBC to feature in a Horizon documentary following the stories of eleven young people with cancer and some of the professionals looking after them. The film crew filmed across the SW and met a number of YP to how they have dealt with their cancer experience, from diagnosis through to treatment and beyond. The programme '[Teenagers vs Cancer: A User's Guide](#)' aired on the BBC in July 2018 to coincide with the 70th Birthday of the NHS. It showcased the SW service but importantly heard from YP directly, in their own words, about their experiences, their thoughts and advice, and their hopes.

Jamie Cargill was awarded a Florence Nightingale Foundation Leadership scholarship in 2017. As part of the scholarship Jamie was hosted by the Danish Cancer Society and invited to undertake a lecturing tour and to visit services for YP in Copenhagen and Aarhus. Subsequently in the summer of 2018 we welcomed members of the Danish TYA service to the SW. They visited services in Bristol and in Taunton and attended the TYA MDaT, a digital platform of interest for services supporting TYAs across Denmark.

12.1 Media Articles

The Sunday Mirror supported Teenage Cancer Trust over the festive period and featured a patient treated in Exeter supported by the TYA CNS in Exeter and Plymouth.

<https://www.mirror.co.uk/news/uk-news/young-mum-who-limb-amputated-13767544>

Dental Health featured a patient treated in the SW and supported by members of the team who wanted to share her story, and let all young people know you are never too young to get cancer.

<https://www.dentalhealth.org/laura-taylor>

The service also featured in an article in the ¹Daily Echo (Bournemouth), ²Newton Abbot Advertiser and ³Dorset Echo (Main)

¹ Daily Echo (Bournemouth) 7.3.2018 Page 17

² Newton Abbot Advertiser 23.2.2018 Page 22

³ Dorset Echo (Main) 9.3.2018 Page 7

13. Objectives For 2019

The overarching objective for 2019 is to consolidate and maintain the model of care evolved to date whilst maintaining a strong focus on innovation and service improvement.

Specific objectives include

1. Secure funding for;
 - a. UHB TYA Ward Sister and TYA specific dietician and physiotherapist (UHB internal business case)
 - b. Additional funding for 0.4wte TYA CNS in Cornwall (local charity funding)
 - c. Regional peer support
 - d. Improved facilities in Bristol with a refurbishment of Area 61
 - e. Continued improvement of facilities in Gloucester and Cheltenham, Taunton and Exeter hospitals
 - f. Attendance of Palliative Care consultant at TYA MDaT
2. Strengthen medical engagement in the network by ensuring that colleagues from the referring MDT's have time to engage with the TYA MDaT on a consistent basis.
3. With support via National Institute for Health Research (NIHR) and NHS England develop a strategy to incrementally improve access to clinical trials across the network
4. Continue to improve access to service activity and governance data from across the network
5. Ongoing prospective evaluation of place of death and development of resources regarding Palliative/Hospice care provision for TYA across the Network
6. Develop service resources for fertility preservation provision across the Network
7. Respond to the CYP Cancer CRG national service review