

B17/S/a

**2013/14 NHS STANDARD CONTRACT
FOR CANCER: TEENAGERS & YOUNG ADULTS**

SECTION B PART 1 - SERVICE SPECIFICATIONS

Service Specification No.	B17/S/a
Service	Cancer: Teenagers & Young Adults
Commissioner Lead	
Provider Lead	
Period	12 months
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

Incidence

There are 1700 patients per year diagnosed with a cancer in the age group 16 to 24 years in England. Overall incidence rates in 15–19 and 20–24-year-olds are 144 and 226 per million within the 15 to 24 population. This breakdown by age to 400 teenagers aged 16 to 18 years and 1,300 young adults aged 19 to 24 years. The spectrum of cancer types in this group covers firstly a large proportion of the patients who suffer from one or other of a small group of cancer types which, although relatively rare in the overall population, are amongst the commonest cancers in this age group. Secondly, there are a minority who develop one of the many cancer types typical of older adults but for various reasons they occur in this situation at an unusually young age.

Cancer rates by age band and sex

Lymphomas showed the highest rates in both age groups. Rates for leukaemias and bone tumours were lower in 20–24 year olds. Higher rates for carcinomas, central nervous system tumours, germ-cell tumours, soft tissue sarcomas and melanoma were seen in the older group. In the last 30 years incidence increased by an average of 1.5% per annum. Significant increases were seen in non-Hodgkins lymphoma (2.3%), astrocytoma (2.3%), germ-cell tumours (2.3%), melanoma (5.1%) and carcinoma of the thyroid (3.5%) and ovary (3.0%). Cancers common in the elderly are uncommon in adolescents and young adults. The incidence of certain cancers in the latter is increasing.

Bone and soft tissue sarcomas, as in childhood, represent numerically important malignancies in adolescents and young adults. The complexity of this tumour group is well recognised and it is covered by separate National Institute for Health and Care Excellence (NICE) Improving Outcomes Guidance (IOG) for sarcoma, as well as the NICE Improving Outcomes Guidance for Children and Young People with Cancer. The Primary Malignant Bone Tumour service is commissioned nationally.

In the 15–24 year age group, germ cell tumours are much more numerous than in childhood and constitute approximately 14% of the total cancers. Similarly, malignant melanoma, which is very rare in children, represents an important group in adolescents and young adults both numerically and clinically.

Cancer in teenagers & young adults (TYAs) ranked by cancer type (%) and age band

	15-19 Yrs % / Rank	20-24 % / Rank
Lymphoma	27.3 (1)	24.0 (1)
Leukaemia	15.1 (2)	7.7 (5)
Carcinoma	11.3 (3)	21.1 (2)
Malignant Brain Tumours	10.8 (4)	7.7 (5)
Bone Tumours	9.7 (5)	3.4 (8)
Germ Cell Neoplasms	9.6 (6)	16.9 (3)
Soft Tissue Sarcoma	6.3 (7)	4.7 (7)
Malignant Melanoma	5.9 (8)	10.1 (4)
Miscellaneous	4.0 (9)	4.4 (9)

(TYA Professor Tim Eden: Slide from TYA Presentation 2009)

Overall rates in both males and females were significantly higher at 20 to 24 years than at 15 to 19 years and rates were significantly higher in males than in females in both age groups. There is however, some variation in the pattern according to diagnostic group. Among leukaemias, rates were higher in males than in females. The incidence of Acute Leukaemia in 15 to 19 year olds was twice that in 20 to 24 year olds. For other Myeloid Leukaemias (ML) the rates are similar in both age groups, but Chronic ML has higher rates at older ages. Rates for lymphomas were significantly higher in the older age group particularly for Hodgkins Disease (HD). For non Hodgkins Lymphoma (HL), rates in males were significantly higher than in females but rates for HD were similar in both sexes.

Diagnostic delay

A number of studies have identified that cancer in teenagers and young adults presents in many different ways. As is well known, these are all very rare in the experience of an individual General Practitioner (GP) and diagnosing cancer in low-risk age groups is difficult.

Evidence base

- Improving Outcomes Guidance for Children and Young People with Cancer. NICE (2005)
- Manual for Cancer Services: Teenage and Young Adult Measures Version 1.0. NCP. (2011)
- National Service Framework for Children and Young People, Standards for Hospital Services, DoH (2007)
- “You’re Welcome” quality criteria: making health services young people friendly” (2011) Department of Health.
- Exploring the Built Environment, The Future’s Company Report for Teenage Cancer Trust (Jan 2010)
- Report for the National Awareness and Early Diagnosis Initiative Cancer in Primary Care: An Analysis Of Significant Event Audits (Sea) For Diagnosis Of Lung Cancer And Cancers In Teenagers And Young Adults 2008 – 2009 Mitchell E, Universities of Dundee, Durham & Glasgow
- Birch JM, Alston RD, Kelsey A, Quinn MJ, Babb P, McNally RJQ. (2002). Classification and incidence of cancers in adolescents and young adults in England 1979-1997. *Brit J Cancer*, 87, 1267-74. eScholarID:1d6343 | DOI:10.1038/sj.bjc.6600647
- NWCIS TYA England data (2005 to 2008) 2012
- “A Blue Print of Care for Teenagers and Young Adults with Cancer”, Teenage Cancer Trust, <http://www.teenagecancertrust.org/workspace/documents/Blueprint-of-care.pdf>

2. Scope

2.1 Aims and objectives of service

Aim

The aim of the service is to provide specialist cancer care for teenagers and young adults aged 16 to 24 years, to improve cancer treatment outcomes, reduce morbidity arising from treatment and support the patient and family throughout their cancer journey and beyond.

Objectives

The designated Principal Treatment Centres (PTC) should support the Teenage & Young Adult Cancer Network Coordinating Group and work collaboratively with the other named designated Teenage & Young Adult hospitals and providers to deliver co-ordinated cancer care and improve outcomes in accordance with the NICE National Guidance for Children and Young People with Cancer (2005).

To deliver quality cancer care and improve outcomes in accordance with the NICE National Guidance for Children and Young People with Cancer (2005).

For Teenagers & Young Adults this includes meeting the national standards for:

- Specifying appropriate referral pathways
- Adhering to and facilitating the cancer specific referral pathways
- Establishment and management of teenage & young adult multidisciplinary teams
- Effective pathways between the principal treatment centre TYA multidisciplinary team and all site specific multidisciplinary teams within the TYA network
- Treating patients in line with TYA cancer network area agreed protocols where a national protocol is not available
- Facilitating transition from children's to teenage and young adult services
- Supporting patients at TYA "designated hospitals" within adult services
- Delivering and supporting palliative care services across the pathway
- Developing and delivering a long term follow up model
- Delivery of age appropriate care and age appropriate settings
- Delivery of care by a workforce specialised in the care of teenager & young adults with cancer
- Supporting families and carers of TYAs with cancer
- Training for staff to deliver the TYA cancer service
- Development and production of appropriate patient and carer information
- Supporting regional and national cancer data collection
- Entry of TYA patients to appropriate clinical trials

2.2 Service description/care pathway

The NICE Guidance on Improving Outcomes in Children and Young People with Cancer (the CYPIOG), requires arrangements to be in place for the diagnosis and management of cancer for patients aged from 16 to the end of their 24th year. For the purposes of national cancer peer review, this age group will be considered to be the 'teenage and young adult' group (TYA). The specification does not prevent patients in the lower part of this age range being treated within designated children's cancer services if they so wish and if this is compatible with local agreements for these cancer services. The arrangements for TYAs differ in some aspects, both from the requirements for children and also those for the rest of the adult population.

The shape of the service

One aim in implementing the service changes for young adult cancer services is to achieve the advantages of an age-appropriate environment and support network but without losing the advantages which have come in adult cancer treatment, associated with implementing the various site-specific cancer guidance and their accompanying practice constraints and changes. The national model requires Teenage & Young Adult services to be managed as a supra-network with appropriate commissioner, clinical and user representation through the TYA Cancer Network and this group fulfils the requirement to support coordination of commissioning across the whole pathway, including designation of services and consistency of policies.

There has been a prior agreement with commissioners that there should be one Teenage & Young Adult Principal Treatment Centre (TYA PTC), with one associated Teenage & Young Adult Multidisciplinary Team (multidisciplinary team). By analogy with the children's measures, there is a requirement for an overall co-ordinating group for the teenage and young adults' cancer network (TYACN).

The national TYA model identifies specific roles for the different providers within the network linked to the choice of pathways for the older age group within TYA. In some instances national pathways will apply to TYA patients and for these designated services eg Primary Malignant Bone Sarcoma patients will need to be referred according to that highly specialised pathway.

Provider roles within the TYA model

The Teenage and Young Adult (TYA) cancer measures specify that

- Patients aged 16 to 18 years should be admitted to a TYA Principal Treatment Centre which should provide age appropriate facilities.
 - Patients aged 19 to 24 years should be offered a choice of access to a TYA Principal Treatment Centre with unhindered access to age- appropriate facilities
- or**
- A hospital designated to provide care for young adults within its adult cancer services.

The Teenage & Young Adult Principal Treatment Centre and TYA Designated Hospitals

The TYA Cancer Network Coordinating Group will have designated the Principal Treatment Centre and certain hospitals outside the PTC which are the designated hospitals to be recommended to TYAs of 19 to the end of their 24th year, should they choose not to be treated in the PTC.

The TYA Principal Treatment Centre will have a TYA multidisciplinary team and should meet minimum requirements for staff and have dedicated inpatient and day case facilities offering age appropriate care.

This specification does not cover commissioning of the TYA designated hospitals. However where these hospitals provide specialised cancer services the TYAs within these services will be included within this. The TYA designated hospital cancer site specific multidisciplinary teams have a requirement to support patient choice, notification of TYA patients and joint planning between multidisciplinary teams and the TYA MDT.

In some instances a patient will have been offered the choice of the TYA PTC or the TYA designated hospital service but may then request treatment at a local hospital. In all cases the local MDT must discuss this with the TYA MDT for joint treatment planning and that so the patient is fully aware of the differences in the services available and what support they can expect to receive.

The Principal Treatment Centre and TYA Designated Hospitals will need specified arrangements described and agreed in the relevant operational policies to support age appropriate care, joint planning, and ongoing support to Teenagers and to Young Adults with cancer wherever patient's have chosen to have their care.

These include:

- Referral guidelines
- Sharing of care between the TYA PTC and treatment facilities in other hospitals;
- Sharing of responsibility for patient management between the TYA multidisciplinary team and site specific multidisciplinary teams;
- Sharing of follow up between the multidisciplinary team and other multidisciplinary teams.

This is in accordance with the TYA cancer measures on:

- Joint treatment planning
- "Choice" for patients aged 19 to 24 years
- Access to clinical trials
- Area wide audits

Service Description

Diagnosis and treatment management

The pathway includes:

- Referral with suspected cancer
- Investigations & confirmation of diagnosis
- Cancer staging and treatment
- Supportive care
- Long term follow up
- And for some patients, palliative care

Treatment may be delivered entirely within the PTC or through TYA designated hospital closer to home. The service should specify the range of cancers and age group of patients covered within the service. The TYA Cancer Network should have agreed clinical indications, guidelines and clinical protocols to guide professional decision making where national protocols are not available. One of the key added values intended to flow from these arrangements is the provision of an age-appropriate environment and support network for these patients, some of whose needs are rather specific to people at this time of life as they make the transition from childhood to adulthood. Another reason for certain needs being specific to this age group is the fact that cancer is in general a rarity in this group and therefore the patients become a rarity amongst their peers. These specific needs are both psychosocial and physical.

Depending on the type of cancer, treatment may include chemotherapy, surgery

and / or radiotherapy. Each of these modalities may be used alone or more often in combination, depending on the particular disease. Care for patients in this age range is mainly provided within inpatient and day care settings and a key difference from adult practice is the smaller proportion of care than can be given in outpatient settings. This is because of the high intensity of the treatment which means patients often become acutely ill during treatment and require a high level of medical support.

The PTC directs the aftercare pathway following treatment, and provides long term follow up to manage the late effects of treatment. Where the patient cannot be cured the service provides palliative and end of life care and bereavement support. The service supports co-ordination of care outside specialist centres through shared care services and in liaison with local community and palliative care services. Where the patient has chosen a TYA Designated Hospital service the PTC will provide support for the TYA specific aspects of care.

The Principal Treatment Centres (PTCs) and designated adult cancer services are required to work with other specialised services and local services to proactively manage transfers and discharges. Services must ensure timely and appropriate communications with services who are expected to provide other parts of the patient's pathway in compliance with national cancer guidance. The Principal Treatment Centre PTC Lead Clinician and PTC Lead Nurse and TYA lead clinicians are members of the TYA Cancer Network and have an important role in developing and delivering the clinical work programme for the TYA Network.

The PTC Lead Clinician and PTC Lead Nurse also have an important role in working with clinicians from TYA designated Hospitals and site specific multidisciplinary team leads to agree compliance with initial and follow up pathways and audit and to ensure effective communication pathways are in place.

PTC staffing

The PTC needs to have the specified staffing arrangements in place including, consultant oncology staffing, middle grade medical cover, nursing staff and social worker, allied health professional and youth worker/ activity co-ordinator.

The TYA multidisciplinary team

The TYA PTC will have a weekly TYA multidisciplinary team. The TYA multidisciplinary teams function is to add value through supporting finalisation of diagnosis and joint planning with the cancer site specific multidisciplinary teams, consideration of the best place of care and psychosocial aspects. This is different to that of the purely site specific multidisciplinary teams in the adult cancer measures and the diagnostic and treatment multidisciplinary team in the children's measures.

The TYA multidisciplinary team should have the specified operational policy core

and extended membership and cover arrangements in place. Its function is different to that of the purely cancer site specific multidisciplinary teams in the adult cancer measures and the diagnostic and treatment multidisciplinary team in the children's measures.

TYA in-patient facility and TYA day care facility

There should be an in-patient and day care facility which is covered by a management policy governing its use. The facility should demonstrate age appropriate care in line with the guidance below:

Chemotherapy

Chemotherapy services and drugs for teenagers and young adults are by definition a specialised clinical activity. Specific facilities are required to prepare chemotherapy and to deliver it to patients and to look after patients who have received chemotherapy. The staff and facilities which are used to deliver this service and the areas of the hospital where this takes place should be declared. Facilities may be compliant through having been reviewed under adult cancer measures. The children & young people and adult chemotherapy / "systemic cancer therapy" service specifications should be adhered to by all providers in relation to their role in the service.

Intrathecal chemotherapy

Services undertaking Intrathecal chemotherapy procedures must be compliant with the national measures written to ensure safety when performing this high risk activity.

Radiotherapy

The radiotherapy service for teenagers and young adults must be at the specified site(s) agreed by the network. The service should offer a comprehensive range of radiotherapy and radionuclide therapy services required for TYA's with cancer. Currently teenagers requiring Proton Beam Therapy (PBT) will need to be referred to the nationally commissioned service accessed through PBT panel for treatment outside the UK. Proton Beam Therapy services will be nationally commissioned within the UK from 2014/15.

Supportive care

Patients require supportive care during the active treatment period. This includes management of febrile neutropenia, nausea, vomiting, central venous access and blood product support. Outcomes in cancer are dependent not only on the safe and effective delivery of treatment, but also on the timely and effective management of the acute and longer-term side effects; improvements in supportive care have played a key role in increased survival. For teenagers this support may continue to be delivered at the PTC or through children's shared care service depending on the local policy agreed within each TYA

Cancer Network (TYACN). For young adults shared care arrangements will need to be developed as appropriate between the PTC and designated hospitals within the relevant TYACN.

Survivorship

The model of care required by teenagers and young adults at the end of cancer treatment is evolving nationally as part of the "National Cancer Survivorship Initiative (NSCI) supported by NHS Improvement. The developing survivorship model of care risk stratifies the patient's need for long term follow up after cancer treatment. It incorporates planning aftercare pathways including both medical and holistic care. The planning is agreed at the end of treatment. Supported self management will be included in the care plan for a proportion of patients and may have an increasing role in the future. The model should ensure access to fertility support is available. Teenagers with the specified cancer-like illnesses will also require transition, and long term follow up and where necessary palliative and end of life care.

Long term follow up / late effects services

Long term follow up covers those patients who have completed their treatment as teenagers and whose aftercare plan will require long term follow up to treat or manage the late effects of their cancer treatment e.g. risk of endocrine dysfunction, impaired cardiac function or impaired fertility, neurological function due to the chemotherapy or radiotherapy treatments required to combat the original cancer. The type of intervention required which will be linked to disease type and the type of treatment they have received for their cancer and therefore the likely late effects of that treatment. In some cases other specialist services will need to be involved such as cardiology to manage the effects of anthracyclines or endocrinology to manage hormone deficiencies after cranial irradiation or services to manage impairment of fertility. These pathways will need to be embedded in the functioning of late effects multidisciplinary teams. Some patients will also require cancer surveillance for relapse or for development secondary malignancy according to agreed policies, depending on their original cancer type.

Transitional care to teenage & young adult / adult services

Transitional care covers those patients who had completed their cancer treatment as children but due to relapse, development of a second malignancy, or as part of the aftercare plan, they now require transition to a different team due to their age. The transition plan should be pre-planned and pro-active so that patients know what to expect if and when transition is required. This may be to a service led by a PTC TYA cancer team or an adult cancer team. In both cases there is a joint responsibility for the referring service and the receiving service to ensure effective transition occurs.

Specialist palliative care

Specialist cancer palliative care advice and treatment is delivered by specialist palliative care teams from the PTC TYA Trust services or linked to the designated adult cancer service. Teams provide expert advice on all aspects of symptom control and psychological support for the teenager / young adult and their family and will be part of a wider paediatric palliative care network. It is recognised these teams will be working with other non cancer agencies to deliver non specialist palliative support e.g. hospices and community nursing teams, and other community based services to provide end of life care and bereavement support. Teenagers with terminal cancer and their families should be made aware of the options for place of death whether that is at home, in a hospice or through other supported care. End of life care should include access to 24 hour expert support.

Specialist psychological support

Care pathways should describe the psychosocial support available to patients and families to support access to treatment. The provision of specialist psychological and appropriate psycho-social support to teenagers, young adults and their families involves multi-agency support and includes particular input from the specialist cancer centre during both the active cancer therapy stage and into follow-up.

Specialist therapies and rehabilitation

Therapy services to support teenagers and young adults with cancer are specialised, these include dietetics, physiotherapy, occupational therapy and rehabilitative support. These specialist services provide ongoing support with the aim of maximising their physical, emotional, cognitive, social and functional potential.

Research

In line with national guidance PTCs will be expected to have clinical trials open to patients which are approved by the National Cancer Research Network and to support national collection of trial data. The PTC as a specialised service has an important role in research and development of the evidence base for effective treatment interventions. In some cases this will be through formal academic links, in others as part of NHS research and development activity. Involvement in clinical research will be recognised as an integral part of the service.

General paediatric care

When treating children, the service will additionally follow the standards and criteria outlined in the specification for Children's Services (attached as Annex 1 to this Specification).

Pregnancy

Pregnant young women with pre-existing conditions as discussed in this specification require assessment and/or management from highly specialist tertiary

maternity care delivered within a dedicated multidisciplinary service staffed by a maternal medicine specialist, a physician, and supporting multidisciplinary team with extensive experience of managing the condition in pregnancy.

In view of this, nationally commissioned condition specific services must have outreach arrangements with highly specialised tertiary maternity units with access to appropriate tertiary medical, surgical, fetal medicine, clinical genetics and level 3 Neonatal Intensive Care services. These specialised maternity services must have a critical mass of activity to maintain expertise, ensure best practice, training opportunities and for the organisational infrastructure, staffing, facilities and equipment to be clinically and economically efficient. They should have robust risk management and performance monitoring processes.

All such women must receive personalised pre-pregnancy and maternity care planning from specialised tertiary maternity services to allow optimal disease management in the context of the pregnancy. This will reduce avoidable morbidity, mortality and unnecessary intervention for mother and baby.

Women with conditions discussed in this specification must be referred immediately once they are pregnant to plan their care. This must include access to termination of pregnancy and specialist advice re contraception. The individualised care plan must cover the ante natal, intrapartum and postnatal periods. It must include clear instructions for shared care with secondary services, when appropriate including escalation and transfer protocols and clear guidelines for planned and emergency delivery.

2.3 Population covered

Commissioners will have defined the population covered by The Teenage & Young Adult Cancer Network Group and served by the TYA Principal Treatment Centre and TYA designated Hospital(s), where applicable. Patients covered by this specification are those treated within specified TYA cancer services at a PTC or within a specialised cancer service within a designated TYA Hospital. The age range used for Peer Review purposes is patients aged 16 to the end of their 24th year, for the diagnosis and management of cancer and this age group will be considered to be the 'teenage and young adult' group (TYAs). This specification does not prevent patients in the lower part of this age range being treated within children's cancer services or patients younger than 16 years being treated within the remit of a designated Principal Treatment Centre TYA service if they so wish and if this is compatible with local agreements for children's and teenage cancer. The TYACNCG will agree initial management, specialised and follow-up pathways for TYA patients across its geographical area. These will be shared with primary and other secondary referrers.

2.4 Any acceptance and exclusion criteria

The service outlined in this specification is for patients ordinarily resident in England;

or otherwise the commissioning responsibility of the NHS in England.* This excludes patients who whilst resident in England, are registered with a GP practice in Wales, but includes patients resident in Wales who are registered with a GP Practice in England.

Referrals should be accepted from any referrer where a teenager or young is suspected of having cancer.

Patients may remain within specialised cancer centre services during the period of active treatment for their specialised cancer and where the care they require for long term follow up or palliative care needs to be managed by these services. Commissioning of services for patients who have chosen to be treated within an adult service and also have a common cancer will be outside the remit of specialised services.

The specialised element of the service includes the TYA PTCs' responsibility to support patients being treated within designated TYA adult services or other highly specialised services, whether or not the patient attends the PTC unit.

National Guidance on the referral of teenagers with suspected cancer is provided and incorporated into local network referral and treatment pathways.

Initial Referral

Patients in the TYA age range are likely to be referred through a number of routes. This is due to the range of symptoms that are likely to be presented and due to the rarity of cancer in this age group which may mean there is no suspicion of cancer at initial referral. To address this commissioners and clinicians working across different parts of the pathway need to ensure policies and procedures are in place that support early recognition of cancer as a possible diagnosis.

A National Awareness and Early Diagnosis Initiative (NAEDI) commissioned report has identified the following advice for primary care:

- There is particular complexity around presentation of bone tumours and sarcomas, and practitioners need to be aware of the non-resolving alleged sports injury.
- It may be appropriate to consider primary care follow-up of musculoskeletal pain thought to be injury related. The reason for ongoing musculoskeletal pain should be identified, particularly if it is of a long duration.
- All neck and axilla lumps should be referred under the 2 week wait rule unless there is an obvious infective cause, in which case the patient should be reviewed.
- It is important to have an appropriate consulting style that would allow young people to feel comfortable enough to explain their symptoms.
- Careful consideration should be given to unusual presentations by teenagers and young adults, and referrals made if the diagnosis is not clear.

2.5 Interdependencies with other services

The Principal Treatment Centre

On-Site Intensive Care Unit

- **Either:**
There should be an intensive care unit (ICU) which accepts patients of the TYA age range, on the same site as the PTC inpatient facility.
- **Or:**
Where such a unit is not on-site, there should be transfer arrangements agreed between the PTC and the providers of any ICU(s) which are used.

TYA Designated Hospitals

These hospitals will be treating patients aged 19 to 24 years who have chosen to be treated within adult cancer services. Specialised cancer site specific services will also be commissioned through NHS England and others may be commissioned by CCGs. TYA Designated Hospitals have specific responsibilities to support TYA care and pathways as described in the cancer measures.

Hospitals which are not TYA PTCs or TYA Designated Hospitals

All hospitals whatever their designation should, after consultation agree the TYACN referral guidelines across all tumour types and contribute to the access to research trials and area wide audit measures.

Hospitals which are neither host hospitals of a PTC nor TYA designated hospitals will still be subject to all relevant measures in the rest of the Manual of Cancer Services, as will the PTC and designated hospitals. In particular, this includes TYA referral pathways, and the 'adult' chemotherapy and acute oncology measures.

Interdependencies with very specialised cancer services

Exceptions to these pathways for TYAs, may arise in cases of very rare clinical situations, requiring management by national services provided for under the NHS specialised services arrangements. These pathways should be documented.

- Retinoblastoma / Eye Tumour services
- Primary malignant bone tumour service
- Choriocarcinoma Services
- Liver transplant cancer related surgery
- Proton Beam Therapy
- Blood & marrow transplantation
- Strategic Clinical Networks
- National Cancer Screening Programmes

The following local commissioners and service providers are highly relevant to the

TYA service.

- Clinical Commissioning Groups
- Community Services
- Local Authorities
- Education services for patients in full time education up to 18 years of age
- Education services for patients in full time / part time education aged 18 to 24 years of age
- Careers and Employment services
- End of Life and Hospice services

Health needs in young people with cancer in the community

CLIC Sargent cancer charity in collaboration with NHS, local authority and academic partners has published the “More Than My Illness” report which reviewed the different needs of teenagers and young adults; particularly needs in the community. Some of the Key messages are summarised below.

Young People say they need ...	Challenges
Clinical care in the community Young people said it was important to get clinical support at home	A disparity in the level of clinical support offered in the community
Education, employment and training It was important to get employment support, and this became more important as age at diagnosis increased	Lack of financial and practical support for post compulsory education
Emotional Had not been able to keep up with a ‘normal’ social life	Difficulties with relating to friends and peers
Social Had not been able to meet someone going through the same thing as them	Not being able to meet other young people in the same situation
Housing It was important to get practical support, and this became more important as age at diagnosis increased	Issues with accessing practical support in the home, for example aids and adaptations, home help, child care
Financial Young people said it was important to get advice and support on money matters, and this became more important as age at diagnosis increased	Difficulties with accessing benefits
General health and fitness Young people said it was important to be able to maintain a healthy lifestyle	Need for support with making healthy lifestyle and sexual health choices

3. Applicable Service Standards

3.1 Applicable national standards e.g. NICE, Royal College

Improving Outcomes Guidance for Children and Young People with Cancer. NICE (2005)

PTC Staffing

The PTC needs to have the specified staffing arrangements in place including, consultant oncology staffing, middle grade medical cover, nursing staff and social worker, allied health professional, appropriate psychological support and a youth worker/ activity co-ordinator. The PTC should ensure training for PTC inpatient beds nurses and day case facility nurses.

The TYA multidisciplinary team

The TYA PTC will have a weekly TYA multidisciplinary team. The TYA multidisciplinary team should have the specified operational policy core and extended membership and cover arrangements in place. Its function is different to that of the purely cancer site specific multidisciplinary teams in the adult cancer measures and the diagnostic and treatment multidisciplinary team in the children's measures.

The TYA multidisciplinary teams function is to add value through supporting finalisation of diagnosis and joint planning with the cancer site specific multidisciplinary teams, consideration of the best place of care and psychosocial aspects. This is different to that of the purely site specific multidisciplinary teams in the adult cancer measures and the diagnostic and treatment multidisciplinary team in the children's measures.

Age appropriate care

The concept of age appropriate care is broader than the provision of physical facilities for young people. Age appropriate care encompasses the requirement for PTCs to ensure an environment, treatment philosophy and training of staff to meet the particular needs of patients in this age group, combined with expertise in cancer in young people and effective interface with cancer site specific expertise. Services outside the PTC also need to support this aim, through the TYA leads identified within each service.

The IOG gives clear guidance that:

- All care for children and young people under 19 years old must be provided in age-appropriate facilities
- Young People of 19 years and older should also have unhindered access to age-appropriate facilities and support when needed at the PTC.
- The TYA peer review measures recognise that some parts of care may be provided within adult services and or through a shared care arrangement. Facilities for patients receiving shared care should be consistent with policy

for the age range of the patients being treated and the designation for that service setting.

TYA in-patient facility

There should be an in-patient facility which is covered by a management policy governing its use whereby it is reserved for the use of patients within the TYA age range with malignant disease and non-malignant haematology.

TYA day care facility

There should be a day care facility (room or rooms) whereby, while it is in use for TYAs, it is reserved for a minimum of the relevant half day at a time; for patients of the TYA age range; for chemotherapy or other outpatient/day case aseptic treatment or procedures.

Age appropriate care: at the principal treatment centre

Teenage & Young Adult (TYA) Team	Expertise in treatment of young people and the cancers found in young people
TYA multidisciplinary team	Cancer expertise and co-ordination of care for TYAs with cancer. Interface with Site Specific multidisciplinary teams
Adult site specific multidisciplinary teams	Access to tumour specific or treatment specific clinical expertise as required.
TYA philosophy	TYA Service / multidisciplinary team Operational Policies e.g. flexible ward routine and visiting hours.
	Recognition of need to support parents / partners and other people with key relationships to the patient
	Awareness of growing independence of patients in this age range
	Patient Information on cancer and support aimed at this age group in different formats
TYA staff	Dedicated TYA Lead Clinicians and TYA Lead Nurses for TYA service and team including support from a Social Worker, Youth Worker, and Allied Health Professionals and palliative care
	It is expected that training programmes for TYA teams and associated staff may include knowledge of: <ul style="list-style-type: none"> • the cancers in this age range and treatments • bio/psycho/social development in this age group • typical concerns of young people with cancer • positive communication with young people
TYA peer support	To provide and facilitate TYA cancer patient peer support e.g. patient support groups, activities.

	Support also means of keeping in touch with their existing friendship group e.g. internet, phone access and social networking
TYA social support	Services that support social functioning and social integration, e.g. regarding finances/benefits, housing, family or other relationships,
	Services that support maintenance of or entry to education, employment and training
TYA network support	PTC to work effectively with designated hospitals for young adults with cancer to support and coordinate care as required and to extend opportunities for care closer to home
Age-appropriate facilities	<p>PTCs are expected to provide dedicated age appropriate facilities where TYA patients are cared for alongside their age-group peers, not with younger children or much older adults. It is suggested that the following are considered:</p> <ul style="list-style-type: none"> • How are privacy and dignity supported in the design and use of clinical spaces? • How do facilities/services enable support from and interaction with family and peer groups? • How do facilities/services facilitate continuation of patients interests, activities, education, employment? • How has patient experience either locally or through national groups informed the provision of the facilities?

Training / Education

All staff should be subject to annual performance appraisal and a policy should be in place to govern this. Clear training policies should be in place to ensure that staff maintain and develop their specialist skills and knowledge which should include:

- How to support delivery of age appropriate care.
- To deliver nurse training in line with cancer measures, including training in chemotherapy skills and management of its consequences in line with the staff members role.
- Medical training in line with above where applicable for chemotherapy
- Access to specialist resource materials.
- Time allocated for mandatory training and to maintain and develop cancer skills.

Patient and carer information

In line with national guidance patient and carer information must be provided which covers generic and tumour specific information for teenagers and young adults with cancer.

The information provided must be age appropriate to the age of the patient and must be provided in a variety of formats. It should follow the principles of the national "Information Prescription"

Patient and carer information must be provided which covers the treatment plan, how to access care out of hours and the shared care arrangements with paediatric oncology shared care units (POSCU) services.

End of Life Care

The provider should provide end of life care in line with NICE guidance and in particular the markers of high quality care set out in the NICE quality standard for end of life care for adults.

Acute oncology service

All hospitals with an Accident and Emergency (A&E) department should have an "acute oncology service" (AOS), bringing together relevant staff from A&E, general medicine, haematology and clinical/medical oncology, oncology nursing and oncology pharmacy. This will provide emergency care not only for cancer patients who develop complications following chemotherapy, but also for patients admitted suffering from the consequences of their cancer. For full details on AOS please refer to the service specification for chemotherapy which is currently being developed.

- National Cancer Peer Review: <http://www.cquins.nhs.uk/>
- National Cancer Peer Review Programme Manual for Cancer Services: Teenage and Young Adults Measures
- National Cancer Action Team Version 1.0 2011
- National Cancer Registry datasets
- National Cancer Waits datasets

4. Key Service Outcomes

4.1 Outcomes

- To ensure patients with cancer are referred and supported in line with the named Teenage & Young Adult Cancer Network Coordinating Groups (TYACNCG) agreed pathways.
- To ensure patients with cancer are treated in line with Cancer waiting times targets
- To ensure patients with cancer are treated in line with the national (NCRN) or international cancer protocols or TYACNCG agreed treatment guidelines.
- To ensure suitable patients with cancer have access to the all clinical trials that are available for their tumour type.
- To ensure that teenagers and young adults have integrated and co-ordinated care across the whole pathway and are supported during their cancer journey.

- To demonstrate one year and five year survival outcomes in line with national and international standards for TYAs with cancer adjusted for case mix.
- To demonstrate responsiveness to patient experience in line with TYA Cancer Network and national feedback from families and children with cancer.
- This document needs to be read in conjunction with network guidelines and referral pathways.
- This document is one element of a number of documents that together provide evidence of strategy for this age group, an agreed specification and guidance on delivery of care.

4.2 Service monitoring

The Teenage & Young Adult Cancer Network (TYACN) require contracts and/or service monitoring criteria to include the following as relevant to the part of the patient pathway and the part of the TYACN in question:

- performance against waiting times
- cancer registration
- specified clinical outcome audits
- clinical trial entry rates
- patient reported outcome measures
- collection of Systemic Anti-Cancer therapy (SACT) dataset

5. Location of Provider Premises

The provider's premises are located at:

List of Teenage & Young Adult Cancer Centres offering care for patients 16 to 24 years inclusive.

The location of other services for teenagers are included for reference

Region	City	Trust(s)	Role
North	Newcastle	Great Northern Children's Hospital	Children & Teenage
	Liverpool	Alder Hey Children's Hospital / Wirral University Teaching Hospital NHS Foundation Trust (WUTH) - Clatterbridge	Children & Teenage / Teenage & Young Adult
	Leeds	Leeds Teaching Hospitals Trust: Leeds General Infirmary / St James Hospital	Children & Teenage / Teenage & Young Adult

	Manchester	Central Manchester University Hospitals: Royal Children's Hospital	Children & Teenage
	Sheffield	Sheffield Children's Hospital / Sheffield Teaching Hospitals	Children & Teenage / Teenage & Young Adult
Midlands & East	Nottingham/ Leicester	Leicester / Nottingham City Hospital Queen's Medical Centre	Children & Teenage / Teenage & Young Adult Unit
	Birmingham	Birmingham Children's Hospital NHS Foundation Trust / University Hospitals Birmingham NHS Foundation Trust (UHB): Queen Elizabeth Hospital	Children / Teenage & Young Adult
	Cambridge	Addenbrooke's Hospital	Children / Teenage Teenage & Young Adult
London	London	Great Ormond Street Hospital / University College London (UCLH) Royal Marsden Hospital / St George's Hospital Royal Marsden Hospital (RMH)	Children / Teenage Teenage / Young Adult
South	Oxford	Oxford University Hospitals: Churchill Hospital Site	Children Teenage / Young Adult Unit
	Southampton	Southampton University Hospital	Children / Teenage & Young Adult Units
	Bristol	University Hospitals Bristol: Royal Children's Hospital / Southmead Hospital	Children / Teenage & Young Adult Units

Designated Teenage & Young Adult Hospitals

Commissioners will have designated Teenage & Young Adult Hospitals in each Region.

The list of these hospitals will be confirmed with commissioners and added to this specification.

ANNEX 1 TO SERVICE SPECIFICATION:

PROVISION OF SERVICES TO CHILDREN

Aims and objectives of service

This specification annex applies to all children's services and outlines generic standards and outcomes that would be fundamental to all services.

The generic aspects of care:

The Care of Children in Hospital (HSC 1998/238) requires that:

- Children are admitted to hospital only if the care they require cannot be as well provided at home, in a day clinic or on a day basis in hospital.
- Children requiring admission to hospital are provided with a high standard of medical, nursing and therapeutic care to facilitate speedy recovery and minimize complications and mortality.
- Families with children have easy access to hospital facilities for children without needing to travel significantly further than to other similar amenities.
- Children are discharged from hospital as soon as socially and clinically appropriate and full support provided for subsequent home or day care.
- Good child health care is shared with parents/carers and they are closely involved in the care of their children at all times unless, exceptionally, this is not in the best interest of the child; Accommodation is provided for them to remain with their children overnight if they so wish.

Service description/care pathway

- All paediatric specialised services have a component of primary, secondary, tertiary and even quaternary elements.
- The efficient and effective delivery of services requires children to receive their care as close to home as possible dependent on the phase of their disease.
- Services should therefore be organised and delivered through "integrated pathways of care" (National Service Framework for children, young people and maternity services Department of Health and Department for Education and Skills, London 2004)

Interdependencies with other services

All services will comply with Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies – Department of Health

Imaging

All services will be supported by a three tier imaging network ('Delivering quality imaging services for children' DOH 13732 March 2010). Within the

network;

- It will be clearly defined which imaging test or interventional procedure can be performed and reported at each site.
- Robust procedures will be in place for image transfer for review by a specialist radiologist, these will be supported by appropriate contractual and information governance arrangements.
- Robust arrangements will be in place for patient transfer if more complex imaging or intervention is required.
- Common standards, protocols and governance procedures will exist throughout the network.
- All radiologists, and radiographers will have appropriate training, supervision and access to continuing professional development.
- All equipment will be optimised for paediatric use and use specific paediatric software.

Specialist paediatric anaesthesia

Wherever and whenever children undergo anaesthesia and surgery, their particular needs must be recognised and they should be managed in separate facilities, and looked after by staff with appropriate experience and training.¹ All UK anaesthetists undergo training which provides them with the competencies to care for older babies and children with relatively straightforward surgical conditions and without major co-morbidity. However those working in specialist centres must have undergone additional (specialist) training² and should maintain the competencies so acquired³ *. These competencies include the care of very young/premature babies, the care of babies and children undergoing complex surgery and/or those with major/complex co-morbidity (including those already requiring intensive care support).

As well as providing an essential co-dependent service for surgery, specialist anaesthesia and sedation services may be required to facilitate radiological procedures and interventions (for example MRI scans and percutaneous nephrostomy) and medical interventions (for example joint injection and intrathecal chemotherapy), and for assistance with vascular access in babies and children with complex needs such as intravenous feeding.

Specialist acute pain services for babies and children are organised within existing departments of paediatric anaesthesia and include the provision of agreed (hospital wide) guidance for acute pain, the safe administration of complex analgesia regimes including epidural analgesia, and the daily input of specialist anaesthetists and acute pain nurses with expertise in paediatrics.

*The Safe and Sustainable reviews of paediatric cardiac and neuro- sciences in England have noted the need for additional training and maintenance of competencies by specialist anaesthetists in both fields of practice.

References

1. GPAS Paediatric anaesthetic services. RCoA 2010 www.rcoa.ac.uk
2. CCT in Anaesthesia 2010
3. CPD matrix level 3

Specialised Child and Adolescent Mental Health Services (CAMHS)

The age profile of children and young people admitted to specialised CAMHS day/in-patient settings is different to the age profile for paediatric units in that it is predominantly adolescents who are admitted to specialised CAMHS in-patient settings, including over-16s. The average length of stay is longer for admissions to mental health units. Children and young people in specialised CAMHS day/in-patient settings generally participate in a structured programme of education and therapeutic activities during their admission.

Taking account of the differences in patient profiles the principles and standards set out in this specification apply with modifications to the recommendations regarding the following

- Facilities and environment – essential quality network for in-patient CAMHS (QNIC) standards should apply (<http://www.rcpsych.ac.uk/quality/quality accreditation/audit/qnic1.aspx>)
- Staffing profiles and training - essential QNIC standards should apply.
- The child/ young person's family are allowed to visit at any time of day taking account of the child / young persons need to participate in therapeutic activities and education as well as any safeguarding concerns.
- Children and young people are offered appropriate education from the point of admission.
- Parents/carers are involved in the child/young persons care except where this is not in the best interests of the child / young person and in the case of young people who have the capacity to make their own decisions is subject to their consent.
- Parents/carers who wish to stay overnight are provided with accessible accommodation unless there are safeguarding concerns or this is not in the best interests of the child/ young person.

Applicable national standards e.g. NICE, Royal College

Children and young people must receive care, treatment and support by staff registered by the Nursing and Midwifery Council on the parts of their register that permit a nurse to work with children (Outcome 14h Essential Standards of Quality and Safety, Care Quality Commission, London 2010):

- There must be at least two Registered Children's Nurses (RCNs) on duty 24 hours a day in all hospital children's departments and wards.
- There must be an Registered Children's Nurse available 24 hours a day to advise on the nursing of children in other departments (this post is

included in the staff establishment of 2RCNs in total).

Accommodation, facilities and staffing must be appropriate to the needs of children and separate from those provided for adults. All facilities for children and young people must comply with the Hospital Build Notes HBN 23 Hospital Accommodation for Children and Young People, NHS Estates, the stationary office 2004.

All staff who work with children and young people must be appropriately trained to provide care, treatment and support for children, including Children's Workforce Development Council Induction standards (Outcome 14b Essential Standards of Quality and Safety, Care Quality Commission, London 2010).

Each hospital who admits inpatients must have appropriate medical cover at all times taking account of guidance from relevant expert or professional bodies (National Minimum Standards for Providers of Independent Healthcare, Department of Health, London 2002). "Facing the Future" Standards, Royal College of Paediatrics and Child Health.

Staff must carry out sufficient levels of activity to maintain their competence in caring for children and young people, including in relation to specific anaesthetic and surgical procedures for children, taking account of guidance from relevant expert or professional bodies (Outcome 14g *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010).

Providers must have systems in place to gain and review consent from people who use services, and act on them (Outcome 2a Essential Standards of Quality and Safety, Care Quality Commission, London 2010). These must include specific arrangements for seeking valid consent from children while respecting their human rights and confidentiality and ensure that where the person using the service lacks capacity, best interest meetings are held with people who know and understand the person using the service. Staff should be able to show that they know how to take appropriate consent from children, young people and those with learning disabilities (Outcome 2b) (Seeking Consent: working with children Department of Health, London 2001).

Children and young people must only receive a service from a provider who takes steps to prevent abuse and does not tolerate any abusive practice should it occur (Outcome 7 Essential Standards of Quality and Safety, Care Quality Commission, London 2010 defines the standards and evidence required from providers in this regard). Providers minimise the risk and likelihood of abuse occurring by:

- Ensuring that staff and people who use services understand the aspects of the safeguarding processes that are relevant to them.
- Ensuring that staff understand the signs of abuse and raise this with the right person when those signs are noticed.
- Ensuring that people who use services are aware of how to raise concerns of abuse.

- Having effective means to monitor and review incidents, concerns and complaints that have the potential to become an abuse or safeguarding concern.
- Having effective means of receiving and acting upon feedback from people who use services and any other person.
- Taking action immediately to ensure that any abuse identified is stopped and suspected abuse is addressed by:
 - Having clear procedures followed in practice, monitored and reviewed that take account of relevant legislation and guidance for the management of alleged abuse
 - Separating the alleged abuser from the person who uses services and others who may be at risk or managing the risk by removing the opportunity for abuse to occur, where this is within the control of the provider
 - Reporting the alleged abuse to the appropriate authority
 - Reviewing the person's plan of care to ensure that they are properly supported following the alleged abuse incident.
- Using information from safeguarding concerns to identify non-compliance, or any risk of non-compliance, with the regulations and to decide what will be done to return to compliance.
- Working collaboratively with other services, teams, individuals and agencies in relation to all safeguarding matters and has safeguarding policies that link with local authority policies.
- Participates in local safeguarding children boards where required and understand their responsibilities and the responsibilities of others in line with the Children Act 2004.
- Having clear procedures followed in practice, monitored and reviewed in place about the use of restraint and safeguarding.
- Taking into account relevant guidance set out in the Care Quality Commission's Schedule of Applicable Publications.
- Ensuring that those working with children must wait for a full CRB disclosure before starting work.
- Training and supervising staff in safeguarding to ensure they can demonstrate the competences listed in Outcome 7E of the *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010

All children and young people who use services must be:

- Fully informed of their care, treatment and support.
- Able to take part in decision making to the fullest extent that is possible.
- Asked if they agree for their parents or guardians to be involved in decisions they need to make.

(Outcome 4I Essential Standards of Quality and Safety, Care Quality Commission, London 2010).

Key service outcomes

Evidence is increasing that implementation of the national Quality Criteria for Young People Friendly Services (Department of Health, London 2011) have the potential to greatly improve patient experience, leading to better health outcomes for young people and increasing socially responsible life-long use of the NHS. Implementation is also expected to contribute to improvements in health inequalities and public health outcomes e.g. reduced teenage pregnancy and STIs, and increased smoking cessation. All providers delivering services to young people should be implementing the good practice guidance which delivers compliance with the quality criteria.

Poorly planned transition from young people's to adult-oriented health services can be associated with increased risk of non adherence to treatment and loss to follow-up, which can have serious consequences. There are measurable adverse consequences in terms of morbidity and mortality as well as in social and educational outcomes. When children and young people who use paediatric services are moving to access adult services (for example, during transition for those with long term conditions), these should be organised so that:

- All those involved in the care, treatment and support cooperate with the planning and provision to ensure that the services provided continue to be appropriate to the age and needs of the person who uses services.

The National Minimum Standards for Providers of Independent Healthcare, (Department of Health, London 2002) require the following standards:

- **A16.1** Children are seen in a separate out-patient area, or where the hospital does not have a separate outpatient area for children, they are seen promptly.
- **A16.3** Toys and/or books suitable to the child's age are provided.
- **A16.8** There are segregated areas for the reception of children and adolescents into theatre and for recovery, to screen the children and adolescents from adult Patients; the segregated areas contain all necessary equipment for the care of children.
- **A16.9** A parent is to be actively encouraged to stay at all times, with accommodation made available for the adult in the child's room or close by.
- **A16.10** The child's family is allowed to visit him/her at any time of the day, except where safeguarding procedures do not allow this
- **A16.13** When a child is in hospital for more than five days, play is managed and supervised by a qualified Hospital Play Specialist.
- **A16.14** Children are required to receive education when in hospital for more than five days; the Local Education Authority has an obligation to meet this need and are contacted if necessary.
- **A18.10** There are written procedures for the assessment of pain in children and the provision of appropriate control.

All hospital settings should meet the Standards for the Care of Critically Ill Children (Paediatric Intensive Care Society, London 2010).

There should be age specific arrangements for meeting Regulation 14 of the Health

and Social Care Act 2008 (Regulated Activities) Regulations 2010. These require:

- A choice of suitable and nutritious food and hydration, in sufficient quantities to meet service users' needs;
- Food and hydration that meet any reasonable requirements arising from a service user's religious or cultural background
- Support, where necessary, for the purposes of enabling service users to eat and drink sufficient amounts for their needs.
- For the purposes of this regulation, "food and hydration" includes, where applicable, parenteral nutrition and the administration of dietary supplements where prescribed.
- Providers must have access to facilities for infant feeding, including facilities to support breastfeeding (Outcome 5E, of the *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010)

All paediatric patients should have access to appropriately trained paediatric trained dieticians, physiotherapists, occupational therapists, speech and language therapy, psychology, social work and CAMHS services within nationally defined access standards.

All children and young people should have access to a professional who can undertake an assessment using the Common Assessment Framework and access support from social care, housing, education and other agencies as appropriate

All registered providers must ensure safe use and management of medicines, by means of the making of appropriate arrangements for the obtaining, recording, handling, using, safe keeping, dispensing, safe administration and disposal of medicines (Outcome 9 Essential Standards of Quality and Safety, Care Quality Commission, London 2010). For children, these should include specific arrangements that:

- Ensures the medicines given are appropriate and person-centred by taking account of their age, weight and any learning disability
- Ensuring that staff handling medicines have the competency and skills needed for children and young people's medicines management
- Ensures that wherever possible, age specific information is available for people about the medicines they are taking, including the risks, including information about the use of unlicensed medicine in paediatrics.

Many children with long term illnesses have a learning or physical disability. Providers should ensure that:

- They are supported to have a health action plan
- Facilities meet the appropriate requirements of the Disability Discrimination Act 1995
- They meet the standards set out in Transition: getting it right for young people. Improving the transition of young people with long-term conditions from children's to adult health services. Department of Health Publications,

End.

Interim for adoption from 01/10/13