Pwyllgor Gwasanaethau Iechyd Arbenigol Cymru (PGIAC)
Welsh Health Specialised Services Committee (WHSSC)

Specialised Services Service Specification: Services for Children with Cancer

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Table of Contents

1. AIM

1.1 Introduction

This document has been developed as the service specification for the planning of cancer services for children in Wales. On 31st March 2011 Welsh Government published the National Standards for Children with Cancer aged 0-15 years. These Standards have been developed to provide a foundation for the NHS in Wales to plan and deliver effective high quality services for children aged 0 up to and including 15 years of age. It should be noted that Standards for older teenagers and young adults with cancer are published in a separate document. Implementation of these Standards will ensure access to high quality cancer services for children in this age range across Wales.

Welsh Health Specialised Services Committee (WHSSC) expect providers to continually monitor progress and compliance against these Standards. Performance against the Standards needs to be based on robust evidence. A national monitoring tool has been developed for use by Local Health Boards and is available online for use on the Cancer National Specialist Advisory Group (Cancer NSAG) webpage.

In line with the Standards, the Children and Young People's Cancer Network (CYPCN) will adopt a process utilising the national self assessment tool to monitor against the Service Specification and Standards. The CYPCN in South Wales will be hosted by the South Wales Cancer Network. The Principle Treatment Centre (PTC) Health Board's Cancer Management Team will report to their Executive Board annually on compliance with the National Standards, on behalf of the full CYPCN. WHSSC will monitor and use the information gathered to report to WHSSC's Quality and Patient Safety Group. An analysis of the reasons for non-compliance with standards will be undertaken and action plans for the CYPCN will be agreed with WHSSC as a result.

The Standards are separated into a number of key objectives, this Service Specification makes reference to the Standards and the objectives throughout and in addition the Standards are attached in Appendix 1.

1.2 Epidemiology

The following section is based on the NHS England Service Specification – 2013/14 NHS Standard Contract for Paediatric Oncology.

Children are diagnosed with a wide range of cancers in the UK. Around 41% are leukaemias and lymphomas and 25% are brain tumours, with the remaining conditions comprising a wide range of solid tumours. Most of the cancers affecting children differ from those affecting adults and occur in different parts of the body. Many respond differently to treatment. Treatment is frequently complex and intensive but cure rates among children are much higher than for most adult cancers; overall more than 75% of children are completely cured. A significant proportion of these will experience long-term side effects from their treatment.

Paediatric oncology is the term used to encompass all malignant conditions among children with cancer, including blood conditions such as leukaemia. The doctors involved (paediatric oncologists and paediatric haematologists) work within a national framework to ensure they provide the most effective care. Care has become increasingly centralised in specialised treatment centres over the last 30 years, which has helped to improve survival rates. Care is guideline and research-driven. Guidelines are developed by the CCLG (Children's Cancer & Leukaemia Group) a national, multi-disciplinary organisation which advances the care of children with cancer through best practice and clinical research.

In Great Britain, the world age-standardised incidence rate has increased by more than two fifths (43%) since the late 1960s, from 107 cases per million children in 1966 – 1970 to 152 cases per million in 2001 – 2005. Between 1966 and 2000 there has been a statistically significant average annual increase of almost 1% per year, although this varies between 0.5% and 2.5% per year by tumour type. The literature suggests a plateau has been reached in childhood cancer incidence rates from the mid-1990s onwards. Whilst some of the worldwide increases are likely to be due to real changes in risk, improvements in the efficiency of systems for the diagnosis and registration of childhood cancers since the 1960s and 1970s will also have played a part.

Cancer in children is rare, with about one in 600 children developing a cancer by age 15 years. There are approximately 1,400 new cases of

cancer among children 0-15 years in the UK each year; an annual incidence rate of approximately 1:7700. Proportionately, this would suggest an annual incidence in Wales of approximately 70 children per year. Across the 0-19 age range, the highest incidence of cancer is among children 0-4 years, reducing among children 5-14, and rising again among teenagers over 15 years. The incidence of childhood cancer in each region is similar throughout the UK.

In children, the most common malignancy is leukaemia, followed by tumours of the central nervous system and then a variety of embryonal tumours. As the age of the patient increases, bone sarcoma and epithelial tumours, which are more commonly seen in adults, are found. In addition, patients across this age range will be at different stages of physical and emotional development and the care setting needs to be responsive to the needs/ age of patients.

Cancer-like disease: There are some very rare cancer-like diseases that are treated under paediatric cancer services. These include:

• Langerhans' Cell Histiocytosis (LCH): LCH is a cancer-like condition that may be treated with chemotherapy. In its more serious forms, LCH can behave like a cancer and is therefore usually treated by children's cancer specialists.
• Haemophagocytic Lymphohistiocytosis (HLH): HLH blood disorders are a range of diseases due to a problem with the red or white cells in the blood. Problems can arise when there are too many or too few of these cells, or when their function becomes uncontrollable.
• Craniopharyngioma: A craniopharyngioma is a benign tumour that develops near the pituitary gland at the base of the brain.

Clinical trials are a core part of the way care is delivered for children with cancer, and are often international because of the small numbers involved. Currently clinical trials exist for approximately 60% of children with cancer and this is expected to rise to 80% with the opening of clinical trials which are still in the set-up phase. This makes the treatment of childhood cancer one of the most research-driven of any service within the NHS.

The commissioning and provision of services for Welsh children needs to take account of this and Welsh children should have equity of access to clinical trials where appropriate.

The National Cancer Research Institute (NCRI) Children's Cancer and Leukaemia Group (CCLG) Clinical Studies Group (CSG) has several subgroups working on the development of clinical trials. In some

cases, e.g. sarcomas, the development of paediatric clinical trials is combined with adult studies in a single Clinical Study Group.

In England the delivery of clinical trials is the responsibility of the National Institute for Health Research (NIHR) Clinical Research Network (NIHR CRN). Currently, clinical research within CCL is supported strategically within NIHR CRN: Cancer by a dedicated national specialty lead for CCL and a children's cancer and leukaemia Lead within the CSG. In recognition of the importance of joint working across the whole of the UK and Ireland, NIHR CRN: Cancer has established a UK and Ireland CCL Clinical Research Forum. The Forum brings together key representatives from each nation to ensure processes and knowledge are shared in order to optimise recruitment to CCL studies. Most clinical trials in paediatric oncology are hosted by the Cancer Research UK Clinical Trials Unit at the University of Birmingham, although other clinical trials units may be involved.

The UK has an early phase trials paediatric network. This is part of the Experimental Cancer Medicine Centre Network (ECMC). Most early phase trials are opened in a small number of selected centres and there are currently no early phase centres open within Wales so patients currently need to travel to centres in other parts of the UK to access specific early phase trials.

1.3 Evidence Base

The evidence base for the service specification is drawn from:

• NICE: *Guidance on Cancer Services: Improving Outcomes in Children and young People with Cancer (2005).*

• *NICE: Children and Young People with Cancer, (2014)*

• Department of Health: *Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies 2008.*

• National Service Framework: Children, Young People and Maternity Services (2004).

• Healthcare Commission: *Improving Services for Children in Hospital (2007).*

- Welsh Government: *National Standards for Children with Cancer aged 0-15* (2011).

- Welsh Government*: Together for Health : Cancer Delivery Plan – A Delivery Plan up to 2016 for NHS Wales and its Partners.*

1.4 Service Model

The National Institute for Health and Clinical Excellence (NICE) guidance on Improving Outcomes in Children and Young People with Cancer (2005) recognises cancer in childhood is rare and includes a wide range of cancers with small numbers of patients with each type of cancer. Hence, in order to improve treatment and survival of cancers, the national approach is to commission these services for large populations of at least 2 million to maximise the opportunities for standardising care and evaluating outcomes.

The service model in England and Wales recognises that children with cancer are different to adults because they are children, and because the cancers common in childhood differ from those common in adults. Children's needs differ according to their developmental stage (emotional, social, psychological and physical) and the need to consider the impact on the wider family of a cancer diagnosis. Indeed, across the age spectrum, children are as different from each other as they are from adults. Therefore a holistic approach to needs assessment is an essential part of service design.

The service model is to have two centralised services (North Wales and South Wales) treating approximately 70 new patients a year in total for the whole of Wales. The principle that underpins the model is that of age appropriate, safe and effective services delivered as locally as possible, not local services as safely as possible. Specialised care is therefore centralised in Principal Treatment Centres (PTCs) for Children's Cancer to ensure depth and breadth of cancer coverage, specialist clinical support and age appropriate care across the age range. The PTC retains overall responsibility for the cancer treatment plan but defined aspects of care are delivered in a Paediatric Oncology Shared Care model provided through designated Units (POSCUs). These services are provided by Health Boards outside the PTC. In most cases the PTC for Children and Teenagers & Young Adults (TYAs) is within the same Health Board or Trust and in all cases they should work closely together.

2. SHARED CARE

Objective 1 of the National Standards for Children with Cancer aged 0 to 15 years states that the aim is to have structured cancer networks to bring together key stakeholders in both planning and providing cancer care within an open, transparent management structure.

The Children and Young People's Cancer Network (CYPCN) is an organisational association between primary, secondary, tertiary and voluntary sector providers, social services and planners with care delivered by multidisciplinary clinical teams within a geographic area. It has been agreed that the CYPCN in South Wales will be hosted by the existing South Wales Cancer Network.

Regular meetings between planners and providers as stakeholder organisations will facilitate review of service provision and ensure uniform standards of care are applied across the Network. The Network will need mechanisms in place to action reorganisation of services where appropriate. Whilst working within the CYPCN, the Chief Executive of the organisation on whose premises care is being delivered remains the accountable officer for the quality of care. Where a clinical team provides care to more than one organisation, clear agreements will be required between organisations about how clinical governance responsibilities are to be carried out. In relation to team working, the recommendations made at the team meeting are advisory, and the responsibility for clinical decisions and actions always rests with the senior clinician under whose care the patient is at that point of their journey.

The CYPCN will be based on a Principal Treatment Centre (PTC) and associated Paediatric Oncology Shared Care Units (POSCUs). Shared care will be designated formally with services provided to a level of complexity as agreed by the PTC. The PTC clinical team will be responsible for directing the care provided in the POSCUs. When the care needs exceed the agreed shared care level the POSCU will refer the patient back to the PTC. Specialist outreach and community nursing services will form an essential part of keeping care local or at home.

When a child is diagnosed with a cancer that is more usually diagnosed in adults it is the responsibility of the PTC to collaborate with the specialist cancer site multi disciplinary team (MDT) in determining the

treatment plan whilst ensuring that care is provided in the paediatric setting.

The PTC will be responsible for the transition of children to young people's and adult services. Flexibility will be needed at the age boundaries to ensure that decisions about where care is to be provided are made in the best interests of each patient.

It is envisaged that there will be two CYPCNs providing services for children and young people with cancer living in Wales. Services provided for the North Wales population will continue to be co-ordinated by the Cancer and Children's Clinical Programme Groups of Betsi Cadwaladr University Health Board and as a result of the service model in place will also need to maintain formal links to the English North West Region's CYPCN. The South Wales Cancer Network that includes Powys has a population that supports a PTC and already hosts the Children's Hospital and a Teenage and Young Adult Unit in Cardiff.

An All Wales Children and Young People Advisory Group (CYPCAG) will oversee implementation of these standards as part of the National Specialist Advisory Group on Cancer. The group will comprise representatives of the two CYPCNs and will support national clinical audit and provide strategic advice and direction to service planners at an all Wales level. It is acknowledged that cancer structures in Wales are under review, and the successor organisation will take on this role when the new structures are implemented.

The following table indicates the level of shared care that can be provided by shared care units under the direction of a PTC and based on the adequacy of experienced medical cover out-of-hours. Levels 1 to 3 detail the highest level of services that may be provided. At each level POSCUs may provide the full or partial range of services. Services not included in the Table below will be provided at the PTC.

<u>Level 1</u>

- In-patient supportive care including management of children with febrile neutropenia.
- Out-patient supportive care, e.g. Central line flushes, re-pass nasogastric tubes, administration of transfusions.
- Out-patient follow up.
- Outpatient oral chemotherapy and dose adjustment within agreed guidelines.
- Outpatient bolus or I.V. chemotherapy.

Level 2

- All components within Level 1.
- Day case infusional chemotherapy.

Level 3

- All components within Levels 1 and 2
- In-patient 24 hour paediatric chemotherapy, excluding diagnosis and initiation of treatment and excluding administration of high does methotrexate.
- Administration of intrathecal chemotherapy if agreed by the CYPCN with a paediatric anaesthetic service is on site.

2.1 Service Providers

The PTCs and POSCUs for Wales are shown below.

South Wales
Principal Treatment Centre - Children's Hospital for Wales, C&V UHB.
POSCU Level One - West Wales General Hospital, Hywel Dda HB
POSCU Level One (in development) - Morriston Hospital, ABM UHB

North Wales
Principal Treatment Centre - Alder Hey Children's Foundation NHS Trust
POSCU Level One - Glan Clwyd Hospital, BCUHB
POSCU Level One – Wrexham Maelor Hospital, BCUHB
POSCU Level One – Gwynedd Hospital, Bangor, BCUHB

Mid Wales
Principal Treatment Centre - Birmingham Children's Hospital NHS Foundation Trust
POSCU Level 3 Princess Royal Hospital, Telford – Shrewsbury and Telford Hospital NHS Trust

2.2 Age Range

This Service Specification applies to children from the age of 0-15 (up to the 16th birthday). For the purpose of this document 'children' refers to all people within this age group.

It is expected that older children are given choice about the service and environment in which they are treated and this includes access to teenage wards and services where available.

Very different issues arise depending on the age and maturity of the individuals whose needs are being addressed. Childhood and adolescence is a time of enormous change, physically, psychologically and socially and this influences the different patterns of malignancy seen, their pathological behaviour, response to treatment and eventual outcomes. Outcomes should encompass more than improved health, in terms of survival, mortality and morbidity, and this is even more of a reality for children whose outcomes need to include the ability to mature successfully into adulthood. The late effects of treatment are particularly relevant in this context.

Hospital services should be delivered promptly, be well co-ordinated with effective communication across boundaries and ensure good patient experience. Every individual must be placed at the centre of their care so they have a smooth journey and confidence in the direction and quality of their care.

2.3 Network Co-ordinating Groups

The co-ordination of care in South Wales will require the establishment of a South Wales Children's Cancer Co-ordinating Group (SWCCCG). This will be established as a sub-group of the South Wales Cancer Network. The PTC and POSCU hospitals within the South Wales clinical network are required to support the work programme of the Group, including writing network-wide policies, referral and treatment guidelines, annual reports, audits and service development plans. Clinicians from North Wales are actively involved in the CYPCNG based around the Alder Hey PTC.

The co-ordination of care in North Wales and Mid-Wales follows the English model of Children's Cancer Network Co-ordinating Groups as hosted by NHS England. The POSCUs in North Wales will continue to fully participate in this work relating to the PTC at Alder Hey Children's Hospital.

2.4 Relationship with other Policy and Service Specifications

This document should be read in conjunction with the following documents:

- Specialised Services Policy: Specialist Fertility Services
- Specialised Services Policy: Bone Marrow Transplant
- Specialised Services Service Specification: Bone Marrow Transplant

3. SERVICE DELIVERY

3.1 Service Pathway

The service model is to be consistent with NICE *Improving Outcomes Guidance for Children and Young People with Cancer* (August 2005). Many of the treatments are complex, intensive and potentially curative. The model of care aims to give access to specific cancer expertise, with access to the range of other paediatric surgical and medical services needed to deliver modern cancer care. One of the main objectives of the model is to facilitate co-ordination of care for patients between different tiers of health services, and with social services and education services.

The dependence of children on their families and the profound effect severe ill health and/or death of a child has on other family members are additional important factors that significantly affect all service planning and delivery.

The Health and Social Care Act 2012 sets out a clear expectation that the care system should consider NICE quality standards in planning and delivering services, as part of a general duty to secure continuous improvement in quality.

In line with Objective 2 of the National Standards for Children with Cancer aged 0 to 15 years, care should be co-ordinated to provide an efficient, effective service to patients. The LHB Cancer Lead Clinician (CLC) is accountable to the Health Board via the Medical Director or Executive Lead for cancer and is responsible for identifying requirements to ensure cancer teams comply with the cancer

standards. The CLC needs to be supported by a senior management team. The CYPCN Team Lead Clinician for Children with Cancer must report to the CLC of the Health Boards where services are provided and is responsible for identifying requirements to ensure the team complies with the National Cancer Standards. The CYPCN Lead Clinician needs to ensure that care is managed by the appropriate specialist cancer team.

For the full outline of Objective 2 within the Standards please refer Appendix 1 of this Service Specification.

The majority of children with cancer are treated within clinical trials and treatment for each type of childhood cancer follows specifically designed trials and protocols (national & international). For patient groups where there is no clinical trial open, a national UK guideline or protocol (in some cases an internationally agreed guideline) is used to guide treatment. Currently there are around 40 open clinical trials covering the majority of childhood malignancies, with further trials in set up due to open shortly. The network co-ordinating group should have agreed clinical indications, guidelines and clinical research protocols to guide professional decision making where national protocols are not available.

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. For Acute Lymphoblastic Leukaemia, the most common childhood cancer treatment may be over a two and half to three year period. Other cancers will usually require shorter treatment protocols.

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 children 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, and these will be in conjunction with other services, as these are developed. 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.

The PTCs and shared care 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 and children's cancer guidance.

3.2 Referral

In line with Objective 5 of the National Standards for Children with Cancer aged 0 to 15 years, children with cancer should be referred, diagnosed and treated in a timely, appropriate fashion. The majority of children with acute or rapidly progressing disease will require prompt diagnosis and treatment. Patients referred urgently with suspected cancer should be offered an appointment with a member of the MDT within 10 working days. This has now been extended to ensure that patients with acute or rapidly progressing disease are not only seen promptly but also complete diagnostic investigations and start treatment within an accepted timeframe that applies generally to all cancers. It should be noted that:-

- that Urgent Suspected Cancer referrals (USCs) should be appointed within 10 working days
- The Urgent suspected cancers (USCs) are to comply with the national 62 day target
- Non urgent suspected cancers (NUSCs) are to comply and meet the 31 day target

Shorter waiting times are required for specific cancers where clinically indicated and this is the case for children with cancer where aggressive cancers require start of treatment as soon as possible and always within one month of receipt of the referral at the hospital. For certain types of cancer the definitive treatment policy is initial surveillance with specific anticancer therapy deferred until such time as it is clinically indicated.

Children may develop a clinical problem while out of hospital at any time e.g. neutropenic fever/haemorrhage. It is therefore essential that children and their carers have immediate access to the MDT managing their care for advice or treatment.

In order to fully comply with Objective 5 of the Standards please refer to the Standards in full which are outlined in Appendix 1.

3.3 Diagnosis, Staging and Treatment

In line with Objective 6 of the National Standards for Children with Cancer aged 0 to 15 years (please refer to Appendix 1 for the full outline of the Standards), children with cancer should be diagnosed, staged and treated promptly and in-line with best practice guidelines. In addition please also refer to Objective 12 of the Standards which aims to ensure that all children and young people receive adequate long term follow up.

It has been accepted that patients treated within a trial setting fare better than those treated outside of a trial setting, and this is thought to be due in large measure to the benefits of treatment according to documented protocols, with details of action to be taken in case of adverse effects, dose escalation etc. Standardisation of referral pathways and clinical protocols across the CYPCN will enable outcome assessment to be performed in a uniform manner, and staff gain greater expertise by concentrating on a lesser number of well-defined protocols. Post treatment rehabilitation, tailored to the individual needs, is essential to achieve the best outcomes for each child and young person.

3.4 Multi-Disciplinary Teams (MDTs)

The aim of Objective 2 of the National Standards for Children with Cancer aged 0 to 15 years is that care provided by teams should be well co-ordinated to provide an efficient, effective service to patients. Cancer care involves a number of different specialists working together as a team. To effectively work as a team, particularly across departments within a Health Board, co-ordination and clinical leadership is required. The LHB Cancer Lead Clinician (CLC) is accountable to the Health Board via the Medical Director or Executive Lead for cancer and is responsible for identifying requirements to ensure cancer teams comply with the cancer standards. The CLC needs to be supported by a senior management team. In each Health Board where there is a designated PTC there will be an identified Cancer Management Team that reflects the manner in which cancer is

treated across the management structures. Each team should include at a minimum; a Cancer Lead Clinician, a designated Lead Manager, the lead Cancer Co-ordinator; a nominated Executive Lead, a designated Lead Cancer Nurse. The CYPCN Team Lead Clinician for Children with cancer must report to the CLC of the Health Boards where services are provided and is responsible for identifying requirements to ensure the team complies with the National Cancer Standards. Please refer to Objective 2 of the Standards for the full requirements.

In addition Objective 4 of the National Standards for Children with Cancer aged 0 to 15 years outlines that the aim is to ensure that cancer care for children is provided by a specialist multidisciplinary team. It outlines that patient care needs to be provided by an appropriate team of specialists to ensure high quality care that is based on a range of expertise within different specialities. For children, the diagnosis of cancer will be confirmed and the subsequent treatment plan directed by the PTC working in partnership with POSCUs. The team will vary as the patient moves through the care pathway from diagnosis and treatment through to follow up and this is reflected within the standards. Team working will support cover for annual leave, sick leave and holidays and will enable the MDT to function at all times. Team membership will need to be reviewed to ensure appropriate input into the management of patients and to reflect new roles such as advanced practitioners as they become established.

The standards require that all clinicians treating children with cancer aged up to and including 15 years will be part of the CYPCN and based in a designated PTC or a linked POSCU to ensure that diagnosis, treatment and patient management decisions are taken on an MDT basis. It is recommended that Paediatric oncologists, haematologists, and POSCU lead clinicians will be members of the CCLG.

Core membership of the PTC diagnostic and treatment MDTs will include at least two of each of the following specialties; there should be a minimum of five paediatric haematologists/oncologists. Core members of the diagnostic and treatment MDT include; paediatric oncologists with responsibility for solid tumours, paediatric haematologists with responsibility for haematological malignancy, paediatric oncologists with an interest in brain tumours, paediatric neuro surgeon, paediatric and neuro pathologist clinical oncologists with subspecialisation in paediatric radiotherapy, paediatric radiologist, paediatric surgeon with an expertise in specialist oncology, pathologist/cytogeneticist, MDT co-ordinator. Other paediatric

specialist personnel on site will include; anaesthetics, radiology, pathology/cytogenetics, oncology pharmacist, nursing establishment in line with Royal College of Nursing Guidance, designated oncology pharmacist, designated lead for psychological and psychiatric services, designated social workers, research nurse, data managers, identified lead nurse, specialist trained nurses for ward and day care, oncology outreach nurses. Core Allied Health Professionals will include; paediatric dieticians, paediatric physiotherapists, paediatric occupational therapists and play therapists. In order to meet the requirements of Objective 4 related to Multidisciplinary Teams please refer to the Standards in Appendix 1.

3.5 Haematological Cancer: Leukaemia and Lymphoma

As leukaemia and lymphomas make up 35% of all malignant disease in childhood and adolescence, this group of patients will generate the largest caseload. (NHS England – 2013/14 NHS Standard Contract for Paediatric Oncology)

3.6 Central Nervous System Tumours

This group of patients will generate the second largest workload. Patients with brain tumours often have complex long term needs due to the impact of the tumour and / or the intensive medical and surgical treatment required to treat them. The arrangements for the different age ranges should be specified, as should the operational relationship to the Neurosciences Centre.

Patients under 16 years old may have neurosurgery at the PTC site and radiotherapy at that or another specified site. In general, chemotherapy and supportive care will be at the PTC. Appropriate cover arrangements should be in place where patients are treated at neuroscience centres which are on a different site from the PTC site. (NHS England – 2013/14 NHS Standard Contrace for Paediatric Oncology)

3.7 Solid Tumours Pathway

Solid tumours comprise a wide range of tumours found in a variety of organs and which normally require management jointly with the relevant medical and surgical team. In the paediatric age group, embryonal tumours predominate with tumours more commonly seen

in adults appearing in adolescence and beyond. It is imperative that all the diagnostic and therapeutic skills are tailored in such a way as to provide expert care in an age appropriate location. Treatment will be provided within a PTC but, where required, appropriate liaison with tumour specific MDTs will be part of the agreed pathway. All suspected solid tumours in children and teenagers aged 16yrs and under are to be referred to the PTC. Referral to a specialist MDT at another site may be necessary for some very rare cancers. Any agreed exceptions to the pathway should be described. (NHS England – 2013/14 NHS Standard Contract for Paediatric Oncology)

3.8 Bone Sarcomas

The complexity of this tumour group is well recognised and it is covered by separate NICE *Improving Outcomes Guidance for Sarcoma*, as well as the NICE *Improving Outcomes Guidance for Children and Young People with Cancer*. Bone sarcoma services are provided in conjunction with one of the English nationally commissioned services for diagnostics, surgery and cancer management of these patients. In all cases children are to be treated according to the network's agreed pathway and will usually receive chemotherapy at the PTC. (NHS England – 2013/14 NHS Standard Contract for Paediatric Oncology)

3.9 Retinoblastoma

The complexity of this tumour group is well recognised and the NICE *Improving Outcomes Guidance for Children and Young People with Cancer* states a specific MDT should manage these patients who are usually diagnosed in the first year of life. These patients are to be managed in conjunction with the English nationally commissioned service. Surgery and specialised radiotherapy are usually undertaken within this service but chemotherapy will usually be delivered at the PTC, but can be within other agreed locations as stated in the network pathways documentation. (NHS England – 2013/14 NHS Standard Contract for Paediatric Oncology)

3.10 Hepatoblastoma

Patients with hepatoblastoma require supra regional services which are provided in Birmingham.

4. TREATMENT MODALITIES

4.1 Surgery

As stated within Objective 9 of the Welsh Government's National Standards for Children with Cancer aged 0 to 15 years**,** all forms of surgery should be undertaken by specialists with appropriate expertise. The majority of diagnostic and surgical procedures required for the investigation and treatment of children with cancer require general anaesthesia. The need for these procedures is usually urgent but not necessary an emergency. The provision of sufficient planned surgical lists with paediatric anaesthetic cover is therefore necessary to provide a timely service provided by clinicians with recognised expertise for the diagnois and surgical treatment (as appropriate) of cancer in children.

The majority of children will require central venous access via a Hickman line or portacath and the timely insertion of these catheters by experienced surgeons is also important.

For full compliance against the Welsh Government's National Standards in relation to surgery please refer to Appendix 1.

4.2 Chemotherapy

In line with Objective 11 of the Welsh Government's National Standards for Children with Cancer aged 0 to 15 years the aim is to ensure that patients receive chemotherapy which is planned, prescribed, delivered and supervised in a safe and effective manner.

The Standard states that, as with all other forms of treatment, the results of chemotherapy are likely to be optimum when it is delivered according to a formal written policy. It is also important that policies are in-line with those in use elsewhere in the UK and worldwide. Where there is substantial deviation, this should be in the context of a formal clinical trial.

Chemotherapeutic agents include other complex, systemic therapies such as biological agents and cytokines. Chemotherapeutic agents are potentially dangerous and fatalities have occurred due to the

inappropriate administration of some chemotherapeutic agents via the intrathecal route. It is therefore essential that chemotherapy is provided by trained specialist staff in a safe environment with appropriate facilities. Standardisation of protocols across the CYPCN will enable outcome assessment to be performed in a uniform manner; and staff gain greater expertise by concentrating on a lesser number of well-defined protocols.

Parts of some treatment regimens can be safely delivered at home. Where this has been risk assessed and found to be a safe option whether administered by appropriately trained community nurses, other health professionals or families this should be supported and adequately resourced.

For full compliance of the Standards please refer to Appendix 1. Objective 11.

4.3 e-Prescribing Chemotherapy in Childhood Cancer

As recommended by NICE (2014) children and young people receiving chemotherapy should have it prescribed using an electronic prescribing system. As outlined by NICE (2014) there are a number of risks associated with prescribing and administering chemotherapy. Electronic prescribing of chemotherapy should be used in all settings to help reduce the risks. At present it is widely used in adult cancer care but not available in all children's chemotherapy services.

Chemotherapy regimens for children and young people are varied and often very complex, and there is a high risk of error in calculating the correct doses, fluid volumes and scheduling. Drug dose and fluid volume calculations are based on weight and body surface area. Electronic prescribing systems perform the calculations and support safer prescribing.

4.4 Radiotherapy

The aim of Objective 10 of the National Standards for Children with Cancer aged 0 to 15 years is to ensure that where required patients receive radiotherapy which is planned, prescribed, delivered and supervised in a safe and effective manner.

As outlined in the Standards, radiotherapy is an important part of the management of many children and young people with cancer. In

relation to brain tumours, accuracy of radiotherapy relates to tumour control with associated avoidance of unnecessary irradiation to normal brain minimising late neuro-cognitive effects.

It is essential that the patient remains still, sometimes for up to 25 minutes, during treatment with radiotherapy. Thus, there are particular challenges in treating infants and young children, who may need to be anaesthetised for their treatment.

As curative radiotherapy commonly requires daily treatment for several weeks, appropriate anaesthetic skills and support need to be easily available. Play therapy is vital in helping young children through this process and may prevent the need for anaesthesia.

Therapeutic radiographers with specific training in the management of children are needed to provide safe and efficient care during radiotherapy through their specialist, detailed knowledge of the planning, delivery and anticipated side effects of radiotherapy. They also enable maintenance of continuity of care during the planning and treatment period for the child and family.

As with other forms of treatment, the results of radiotherapy are likely to be optimum when it is delivered according to a formal written policy specifying dose, fractionation, overall treatment time, planning technique and means of verification plus other appropriate QA measures. This is especially true of radical (curative) therapy, where a uniform approach is necessary to be able to evaluate outcomes. It is also important that policies are in line with those in use elsewhere in the UK and worldwide. There there is substantial deviation, this should be in the context of a formal clinical trial. Palliative treatments will need to be individualised on a more frequent basis, but the overall approach shold conform as closely as possible to written policy.

There are circumstances where evidence exists for the superiority of one form of technology over another. An example is the use of conformal radiotherapy in some pelvic malignancies, as a means of reducig treatmet-related side effects. Networks need to have a strategy to ensure that patients for whom such technology is optimum are able to access it, even if this means crossing Health Board/Trust or Network boundaries. In certain cases, for example proton therapy, new technologies may not be available in the UK and a collaborative equitable approach is recommended. The Department of Health have established a UK referral panel to manage the referral of appropriate children for proton therapy abroad until such time as a facility is available in the UK.

The general quality of procedures in the radiotherapy department will be reflected in externally modulated quality schemes as originally specified by Quality Assurance in Radiotherapy (QART).

In order to comply with the Standards in relation to radiotherapy please refer to Objective 10 in Appendix 1.

4.5 Blood and Marrow Transplantation

The PTC should state where blood and marrow transplantation (BMT) services are provided and achieve JACIE (accreditation standards for stem cell transplantation) accreditation of the BMT services with unified protocols and guidelines. The service will be managed in age related units, with close interaction between the units and across the sites. (NHS England – 2013/14 NHS Standard Contract for Paediatric Oncology) Reference should be made to the Service Specification for BMT .

4.6 Supportive Care

Children 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. (NHS England – 2013/14 NHS Standard Contract for Paediatric Oncology)

4.7 Psychosocial Support

Care pathways should describe the psychosocial support available to children and families during and beyond cancer treatment. This involves multi-agency support and addresses the wider social, psychological and emotional needs of the child and family. It requires a holistic approach (starting from a core Holistic Needs Assessment) and continuity of care (requiring the support of an identified Key Worker).

Psychosocial support is provided to families by a range of different health and social care professionals across PTC, POSCU and

community sites who require access to appropriate training e.g. Advanced Communications Skills training. (NHS England – 2013/14 NHS Standard Contract for Paediatric Oncology)

4.8 Specialist Psychological Support

Standard 4.4 of the National Standards for Children with Cancer aged 0 to 15 outlines that the PTC will have access to a designated lead for psychological and psychiatric services. There should be ready access to neuropsychology for the assessment and input for children with acquired or treatment related problems and specialist psychology, and liaison psychiatric services to address more complex psychological morbidity associated with cancer treatment.

4.9 Play Specialists

Standard 4.2 of the National Standards for Children with Cancer aged 0 to 15 years outlines that play therapists are core allied health professionals to the diagnostic and treatment multi-disciplinary team. Support from a play specialist can speed up how long a child takes to feel prepared for any procedure, can reduce referrals to psychology and can greatly enhance patient experience. Play specialists play a crucial role in providing information to children, helping to manage pain and providing socio-emotional support and are members of the psycho social MDT. Play is particularly important for those children under 5 for whom there is the highest incidence of cancer.

4.10 Social Work

Standard 4.6 of the National Standards for Children with Cancer aged 0 to 15 years outlines that the POSCU MDT will include a social worker. Support from social workers is an essential part of this service. The service may encompass, supporting families, supporting children within complex family situations, formal safe guarding issues, as well as specific and general advice to the family on housing, financial and other support for daily living. Social workers play a crucial role in providing information to families, and as part of the psycho-social MDT.

4.11 Educational Support

Educational support is an essential part of this service. The service may be delivered through hospital based schools, links with the child's own school or through facilitating educational support at home. Teachers play a crucial role in ensuring the child's educational attainment is optimized and are key members of the psycho-social-MDT. (NHS England – 2013/14 NHS Standard Contract for Paediatric Oncology)

4.12 Survivorship

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 as the care plan for a proportion of patients and may have an increasing role in the future. The model should ensure that access to fertility support is available, as approximately 15% of patients have a high risk of future fertility problems because of their cancer treatment. Children and young people with cancer and their parents or carers should have the risks discussed with them and be advised about their options for fertility preservation before cancer treatment starts.

Children with the specified cancer-like illnesses will also require transition, and long term follow-up and, where necessary, palliative and end of life care.

4.13 Long Term Follow Up and Care

In line with Objective 12 of the Welsh Government's National Standards for Children with Cancer aged 0 to 15 years, the aim is to ensure that all children and young people receive adequate long term follow up care.

With increasing survival, the physical, emotional and social sequelae, which may impair the quality of life in the long term, because more important. Although many of those cured of cancer during childhood or young adulthood will return to good health, others will experience significant late sequelae. Objectives 3 and 4 also include standards that address issues in relation to late effects and should be read alongside the additional standards outlined here.

Sequelae can occur at any time during or following completion of therapy. They include problems such as impairment of endocrine function (for some including infertility, abnormal growth and development or bone mineral accretion), cardiac and neurological impairment, cognitive decline (for example, following treatment for tumours of the CNS) and psychological effects. It should be recognised that children may have problems with learning because of schooling missed as a result of treatment and longer term cognitive disability for example following radiotherapy for brain cancer. Some patients may have significant disability for example loss of limb or sight.

There is also an increased risk of developing a second cancer in some patients. On average, 4% of childhood cancer survivors develop a second primary malignancy within 25 years of diagnosis although for certain diagnoses this figure is higher. Radiotherapy is a particular risk factor. The risk of second malignancy, which can occur many years after the primary diagnosis, is estimated to be between four and six times the risk in the general population.

Because patients experiencing late effects are likely to present first to a GP and not to those involved in their original treatment, continued communication with primary care is important. Referral needs to be a specialist with an understanding of the patient's previous disease and therapy. Therefore coordination and communication across MDTs and between the PTC and the POSCU are very important. Although most of the treatment needs to be given in the PTC it is expected that, wherever possible, follow-up will be delivered closer to home. Furthermore as survivors become adults they often need referral to a variety of specialists, which is much more appropriate close to the patient's home.

For compliance against the Standards please refer to Appendix 1 Objective 12.

4.14 Transitional Care to Teenage & Young Adult / Adult Services

Transitional care applies to those patients who have 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 that effective transition occurs. Standard 12 of the Welsh Government's National Standards for Children with Cancer aged 0 to 15 years (Appendix 1), requires that each long-term survivor has a named key worker and that a care plan is developed for every long-term survivor in partnership with the child, young person and their family. Fertility advice should also be made available to all long-term survivors.

4.15 Families and Carers

The aim of Objective 3 of the Welsh Government's National Standards for Children with Cancer aged 0 to 15 years is to ensure that patients and/or carers have support and all the information they require regarding the diagnosis, treatment and treatment care plan. Please refer to Appendix 1 for the required standards in full.

4.16 Specialist Palliative Care

The aim of Objective 13 of the Welsh Government's National Standards for Children with Cancer aged 0 to 15 years, is to ensure that all patients receive adequate assessment of, and provision for, palliative care needs at all times and in every setting. This includes care of dying patients, their families and carerers.

As outlined within the standards, the palliative approach may be applicable at any stage of a patient's illness and incorporate the particular needs of the dying patient. It is the responsibility of all health professionals caring for those with progressive life-threatening disease, informed by knowledge of palliative care principles and practice and supported by a specialist palliative care team. All children must have access to general services and support as outlined in the CYPSS Palliative Care standards. All health professionals engaged in the care of children with cancer should receive training to allow adequate assessment and delivery of general palliative. In order to fully comply with the requirements of the Standards please refer to Appendix 1.

4.17 Specialist Therapies and Rehabilitation

Therapy services to support children and teenagers with cancer are specialised, these include Dietetics, Physiotherapy, Occupational Therapy and rehabilitative support. These specialist staff should be available as a minimum in line with the standards set in the children's cancer measures to support MDT working and to provide ongoing support to children and teenagers with the aim of maximising their physical, emotional, cognitive, social and functional potential. Standard 4.2 of the National Standards for Children with Cancer aged 0 to 15 years outlines that core allied health professionals to the diagnostic and treatment MDT will include paediatric physiotherapy, paediatric dieticians, paediatric occupational therapists and play therapist.

4.18 Third Sector Organisations

The pathway of support for children and young people with cancer is enhanced and supported by a number of charities who provide a holistic approach and a range of services including palliative care, specialist social care provision, specialist paediatric oncology nurses, information services and grants. Whilst these services are not commissioned directly but provided by charitable funding, they are important in supporting families and patients and in providing commissioners with comprehensive information and guidance around services.

4.19 Population Covered

The population covered is the whole of Wales subject to the current guidance regarding the border population. For the purpose of commissioning health services this includes patients who are resident in England but who are registered with a GP practice in Wales.

4.20 Interdependencies with Other Services

Children's cancer services have a range of critical interdependencies with other clinical services – notably Paediatric Infectious Diseases, Paediatric Intensive Care, Paediatric Anaesthesia and pain management, Paediatric Surgery and Clinical Haematology and Blood and Marrow Transplant.

These co-located services and interdependencies are set out in full in the Department of Health report 2008 "*Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework for Critical Interdependencies*".

The recommendations of the English Review of Paediatric Neurosurgery (2011), when completed, will affect services for North Wales patients.

5 FACILITIES

5.1 Inpatient Care

The hospital and wards which are providing inpatient cancer diagnosis, cancer treatment expertise, psycho-social support and surgical cancer therapy for children should be documented. The relationship to the inpatient care of young people aged 16 – 24 years ward(s) should be described to demonstrate consistency with these arrangements.

5.2 Day Care Facilities

There will be separate day care facilities for children with waiting and play areas. Day care will include outpatient chemotherapy, blood transfusion, patient assessment, bone marrow examinations, administration of intrathecal chemotherapy and preparation for bone marrow harvest. General anaesthetic facilities for children and young people undergoing painful procedures (bone marrow examination and administration of intrathecal chemotherapy) will be provided at the PTC. Some of these services can be provided at shared care sites in line with the Shared Care Agreement.

5.3 Outpatient Facilities

There will be separate outpatient facilities for children.

5.4 The Chemotherapy Pharmacy Service

The oncology pharmacy service supporting each chemotherapy service will be reviewed against the national cancer standards, some of which

are derived from standards applicable to pharmacy services reviewed as part of the peer review of "adult" cancer services.

Radiotherapy treatment will be provided at a named site specified as suitable to treat children with cancer. Where general anaesthesia is required this is provided by specifically trained staff and in facilities suitable for paediatric anaesthesia.

5.5 High Dependency Care / Intensive Care

Children requiring high dependency / intensive care will be rapidly assessed by the 24 hour on site paediatric and anaesthetic teams and transferred to the PICU as required.

5.6 Imaging

The MDT should have access to high quality imaging services (Objective 7 – National Standards for Children with Cancer aged 0 to 15 years)

As stated within the Welsh Government's National Standards for Children with Cancer aged 0 to 15 years, imaging is important in the diagnosis and staging of many patients with cancer. Waits for imaging investigations may introduce significant delays before clinical diagnosis is confirmed and appropriate treatment can be instituted. This is particularly true for complex investigations.

Imaging departments need to work to high standards of service delivery that encompass management systems, waiting list management, procedural work, examination reporting, provision of clinical advice and quality assurance.

The Stardards require that:

- Imaging departments should provide clear, written information to its Clinical Network (s) on the range of investigations provides, and their availability. Where availability is limited or intermittend, particularly for complex investigations, ther should be written alternative referral pathways agreed with the CYPCN.
- Standardised imaging protocols for staging should be agreed with the CYPCN.
- Staging should be reported in a standardised format agreed within the CYPCN.

- All reports should, as a minimum, allow assessment of that component of TNM status which relies on diagnostic radiology.
- For children where a diagnosis of suspected cancer has been made outside the PTC, digital or hard copy of relevant images will be forwarded to the PTC at or prior to transfer.

In order to achieve this, initial work is required to unify imaging protocols and staging reports between different hospitals. This will avoid additional unnecessary studies and make clinically meaningful comparison and review of services and outcomes possible.

5.7 Pathology

The MDT should have access to high quality pathology services (Objective 8 - National Standards for Children with Cancer aged 0 to 15 years)

As stated within the Welsh Government's National Standards for Children with Cancer aged 0 to 15 years, pathology laboratories should work to high standards of service delivery that encompass management systems, diagnosis, specimen reporting, provision of clinical advice and quality assurance.

Adequate and appropriate information in pathology reports is essential to inform prognosis, plan individual patient treatment, support epidemiology and research to evaluate clinical services and support clinical governance. Specialist histopathologists should be members of a relevant specialist UK society and participate in the relevang specialised national External Quality Assessment (EQA) scheme. Diagnosis of sarcoma and lymphoma is complex and good practice guidance supports the use of specialist histological review of all cases at Principal Treatment Centres. In order to comply with the Standards fully please refer to Appendix 1.

5.8 Education and Training

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.

5.9 Patient Centred Care and Carer Information

Appropriate information whether provided in written form or via face-to-face communication is required to support childen and their families/carers throughout the cancer journey. All healthcare professionals need to be sensitive to potential problems with communication, with information being tailored to the needs of individual patients. Parents and children need appropriate information in make informed choices abut treatment. Children benefit from age specific information in order to participate in these choices. Special training can improve communication skills in general and will provide for effective communication of the diagnosis, treatment options and treatment care plan. The psychological needs of children and their families are often not address and when facing the diagnosis of initial or recurrent cancer in a child, may benefit from specific psychological or psychiatric therapy. The input of psychological support cannot be underestimated.

It is also recognised, and is an existing requirement that accommodation for parents/families is required to enable them to be near their child during treatment. (National Standards for Children with Canger aged 0 to 15 years). Please refer to Appendix 1, in order to review the standards for compliance in Objective 3 of the Standards.

6. QUALITY AND PATIENT SAFETY

All providers must enable patient, carer and advocate's informed participation and to be able to demonstrate this. Provision should be made for patients with communication difficulties or other special needs, and for children.

Any increasing trend in complaints, or any serious adverse incidents must be reported to the WHSSC Medical Director immediately.

6.1 Quality Standards

Providers are expected to comply with the following national Standards:

- NICE Guidance on *Improving Outcomes in Children and Young People with Cancer* (2005)

- National Standards for Children with Cancer aged 0 to 15 years.
- NSF for Children, Young People and Maternity Services in Wales
- NICE Children and Young People with Cancer Quality Standard (2014)
- St*andards for the Care of Critically Ill Children* (Paediatric Intensive Care Society, London 2010).
- Health care service standards in caring for neonates, children and young people. Royal College of Nursing (2011).

6.2 Putting Things Right: Raising a Concern

Whilst every effort has been made to ensure that decisions made under this policy are robust and appropriate for the patient group, it is acknowledged that there may be occasions when the patient or their representative are not happy with decisions made or the treatment provided. The patient or their representative should be guided by the clinician, or the member of NHS staff with whom the concern is raised, to the appropriate arrangements for management of their concern:

- When a patient or their representative is unhappy with the decision that the patient does not meet the criteria for treatment further information can be provided demonstrating exceptionality. The request will then be considered by the All Wales IPFR Panel.
- If the patient or their representative is not happy with the decision of the All Wales IPFR Panel the patient and/or their representative has a right to ask for this decision to be reviewed. The grounds for the review, which are detailed in the All Wales Policy: Making Decisions on Individual Patient Funding Requests (IPFR), must be clearly stated. The review should be undertaken, by the patient's Local Health Board;
- When a patient or their representative is unhappy with the care provided during the treatment or the clinical decision to withdraw treatment provided under this policy, the patient and/or their representative should be guided to the LHB for NHS Putting Things Right. For services provided outside NHS Wales the patient or their representative should be guided to the NHS Trust Concerns Procedure with a copy of the concern being sent to WHSSC.

7. PERFORMANCE MONITORING AND INFORMATION REQUIREMENTS

7.1 Performance Monitoring

WHSSC is responsible for commissioning services in line with this specification. This will include agreeing appropriate information and procedures to monitor the performance of organisations.

For the services defined in this policy the following approach will be adopted:

- **Service providers to evidence quality and performance controls as described below**
- **Service providers to evidence compliance with standards of care as described below**
- **A formal annual audit day to be arranged including both the North and South Wales network co-ordinating groups**

WHSSC will conduct performance and quality reviews on an annual basis in line with the Welsh Government National Standards for Children with Cancer aged 0 to 15 years. Standard 2.7 states that each CYPCN will adopt a process, utilising the national self assessment tool, by which the Health Board Cancer Management Team hosting the PTC and linked POSCUs report to their Health Board/Trust Boards at least annually on compliance with National Standards for Children and Young People with Cancer. Standard 2.8 outlines that an analysis of the reasons for non-compliance with standards is undertaken with action plans, agreed by the CYPCN and WHSSC drawn up as a result. Health Boards and Trusts to provide documentation of agreed action plans.

7.2 Key Performance Indicators

The Welsh Cancer Intelligence and Surveillance Unit has responsibility for cancer registrations on behalf of the Welsh Assembly Government. The National Cancer Intelligence Centre at the Office for National Statistics (NCIC-ONS) collates cancer registration data nationally for England, Wales and Scotland.

The Welsh Government has developed National Standards for Children with Cancer aged 0 to 15 years. A monitoring tool has been developed in accordance with this by the Cancer National Services Advisory Group and is available for use on their webpage. All providers are expected to monitor progress against these standards on an on going basis.

All PTCs providing services for Welsh children are expected to register all cases and to be able to compare outcomes with the other PTCs in England. Completeness of data is important and all PTCs should aim for 100% registration.

- 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 or international children's cancer protocols (UKCRN Study Portfolio managed by NCRN) or network agreed treatment guidelines.
- To ensure suitable patients with cancer have access to all clinical trials that are available for their tumour type.
- To ensure that parents and children 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 children with cancer adjusted for case mix.
- To demonstrate responsiveness to patient experience in line with local and national feedback from families and children with cancer.

7.3 Outcomes and Quality Monitoring

At the annual Audit Day PTC providers should record and be able to present evidence and data in line with the key performance indicators above and in addition be able to present evidence and present on the following:-

- Compliance against the National Standards for Children with Cancer aged 0 to 15 years.
- Compliance against the Quality Standards listed in the Quality Section above.
- Survival rates as specified above.
- Performance against waiting times.
- Cancer registration rates.

- Clinical trial entry rates.
- Patient/family reported satisfaction.
- Rates of assignment of a Key Worker to each child with cancer, from the point of diagnosis onwards, to coordinate their ongoing care.
- provision of each child, family and the GP with an "end of treatment" summary to inform the care plan, or where appropriate a transition plan.

- lengths of stay and discharge destination.
- capacity and staffing in line with national measures.
- safe use of chemotherapy in line with national measures.
- multi-disciplinary training undertaken.
- how users and carers are involved.
- information provided to patients and carers.
- adverse and near-miss incidents and complaints.
- The number of patient safety incidents in children related to chemotherapy prescriptions.
- Results of Peer Review for Children with Cancer when undertaken in 2016/2017

7.4 Audit and Clinical Governance

Providers should have an active audit programme and be able to demonstrate that they have implemented the NICE Improving Outcomes (IOG) for children and young people with cancer. In line with Objective 4 of the National Standards for Children with Cancer aged 0 to 15 years, a programme of audit, defining performance against the cancer standards will provide cancer networks, MDTs, Health Boards, Trusts, WHSSC, the public and the Welsh Government with the information needed to maintain and improve cancer services.

By developing an effective audit programme, networks and MDTs can also define whether any weaknesses are due to organisational factors, or to resource issues, a distinction that is of the utmost importance in seeking the appropriate remedy.

Peer Review

The Welsh Cancer Networks is undertake a programme of peer review which will be applied to the Children's Cancer Services for Wales. The North Wales service also participates in the peer review process that is led by Merseyside, Cheshire and North Wales CYPCNG.

The result of the peer review processes should be shared with WHSSC to inform service planning and future commissioning needs.

A programme of audit, defining performance against the standards will provide the Cancer Networks, MDTs, Health Boards/Trusts, WHSSC, the public, and the Welsh Assembly Government with the information needed to maintain and improve cancer services. Identifying and rewarding areas of strength are important for morale and motivation. By developing an effective audit programme, Networks and MDTs can also define whether any weaknesses are due to organisational factors or to resource issues, a distinction that is of the utmost importance in seeking the appropriate remedy.

8. EQUALITY IMPACT AND ASSESSMENT

The Equality Impact Assessment (EQIA) process has been developed to help promote fair and equal treatment in the delivery of health services. It aims to enable Welsh Health Specialised Services Committee to identify and eliminate detrimental treatment caused by the adverse impact of health service policies upon groups and individuals for reasons of race, gender re-assignment, disability, sex, sexual orientation, age, religion and belief, marriage and civil partnership, pregnancy and maternity and language (welsh).

This policy has been subjected to an Equality Impact Assessment.

The Assessment demonstrates the policy is robust and there is no potential for discrimination or adverse impact. All opportunities to promote equality have been taken

Appendix 1

Welsh Government – National Standards for Children with Cancer aged 0 – 15 years.

Topic – Organisation

Objective 1 – To structure cancer networks such that they bring together key stakeholders in both planning and providing cancer care within an open, transparent management structure.

The Children and Young People's Cancer Network (CYPCN) is an organisational association between primary, secondary, tertiary and voluntary sector providers, social services and planners with care delivered by multidisciplinary clinical teams within a geographic area. Regular meetings between planners and providers as stakeholder organisations will facilitate review of service provision and ensure uniform standards of care are applied across the Network. The Network will need mechanisms in place to action reorganisation of services where appropriate. Whilst working within the CYPCN the Chief Executive of the organisation on whose premises care is being delivered remains the accountable officer for the quality of care. Where a clinical team provides care to more than one organisation, clear agreements will be required between organisations about how clinical governance responsibilities are to be carried out. In relation to team working, the recommendations made at the team meeting are advisory, and the responsibility for clinical decisions and actions always rests with the senior clinician under whose care the patient is at that point of their journey.

The CYPCN will be based on a Principal Treatment Centre (PTC) and associated Paediatric Oncology Shared Care Units (POSCUs) Shared care will be designated formally with services provided to a level of complexity as agreed by the PTC. The PTC clinical team will be responsible for directing the care provided in the POSCUs. When the care needs exceed the agreed shared care level the POSCU will refer the patient back to the PTC. Specialist outreach and community nursing services will form an essential part of keeping care local or at home.

When a child is diagnosed with a cancer that is more usually diagnosed in adults it is the responsibility of the pTC to collaborate with the specialist cancer site multi disciplinary team (MDT) in

determining the treatment plan whilst ensuring that care is provided in the paediatric setting.

The PTC will be responsible for the transition of childen moving to young people's and adult services. Flexibility will be needed at the age boundaries to ensure that decisions about where care is to be provided are made in the best interests of each patient.

It is envisaged that there will be two CYPCNs providing services for children and young people with cancer living in Wales. Services provided for the North Wales population will continue to be co-ordinated by the Cancer and Children's Clinical Programme Groups of Betsi Cadwaladr University Health Board and as a result of the service model in place will also need to maintain formal links to the Cheshire and Merseyside CYPCN. The South Wales Cancer Network that includes Powys has a population that will support a PTC and already hosts the Children's Hospital and a Teenage and Young Adult Unit in Cardiff however, POSCUs are less well developed.

An All Wales Children and Young People Advisory Group (CYPCAG) will oversee implementation of these standards as part of the National Specialist Advisory Group on Cancet. The group will comprise respresntatives of the two CYPCNs and will support national clinical audit and provide strategic advice and direction to service planners at an all Wales level.

Standard	Examples of monitoring criteria
1.1 The Welsh Health Specialised Services Committee (WHSSC) will designate PTC and the level of shared care to be provided by each linked POSCU participating in the CYPCN. This must be in writing, taking account of NICE service Guidance with advice from the all Wales CYPCAG.	1.1 Documentation to be provided by WHSSC detailing: a designated PTC; b named POSCUs and agreed levels of care provided.
1.2 Each CYPCN will have a named lead covering childhood cancer from each associated Cancer Network.	1.2 Documentation to be provided by the CYPCN.
1.3 The CYPCN membership, management arrangements and	1.3 The establishment agreement detailing the CYPCN

accountability will be documented.	membership and management accountability to be held by the WHSSC.
1.4 The CYPCN should ensure that clinical governance lines of accountability for clinical teams within the PTC and POSCUs are agreed and documented.	1.4 Documentation to be provided detailing accountability for clinical governance.
1.5 The CYPCN will produce a Service Development Plan that is agreed by the CYPCN Board and the all Wales CYPCAG and is updated annually.	1.5 a The service development plan, approved by the CYPCN Board, is available for external peer review. b The Network to report to the WHSSC on implementation of service plans.

Objective 2: Care provided by teams should be well co-ordinated to provide an efficient, effective service to patients.

Rationale: Cancer care involves a number of different specialists working together as a team. To effectively work as a team, particularly across departments within a Health Board, co-ordination and clinical leadership is required.

The LHB Cancer Lead Clinician (CLC) is accountable to the Health Board via the Medical Director or Executive Lead for cancer and is responsible for identifying requirements to ensure cancer teams comply with the cancer standards. The CLC needs to be supported by a senior management team.

The CYPCN Team Lead Clinician for Children with cancer must report to the CLC of the Health Boards where services are provided and is responsible for identifying requirements to ensure the team complies with the National Cancer Standards.

The CYPCN Lead Clinician needs to ensure that care is managed by the appropriate specialist cancer team.

Standard	Examples of monitoring criteria
2.1 In each Health Board where there is a designated PTC there will be an identified Cancer	2.1 Documentation detailing names and designation and a description of how the

Management Team that reflects the manner in which cancer is treated across the management structures. Each team should include at a minimum: a a Cancer Lead Clinician (CLC); b a designated Lead Manager; c the lead Cancer Co-ordinator; d nominated Executive Lead; e a designated Lead Cancer Nurse.	management team relates to internal management structures.
2.2 The CLC will be appointed by the Health Board and have recognised dedicated sessional time with administrative and senior management support.	2.2 Job plan to detail role, sessional time and management support for CLC.
2.3 The CLC will attend both Health Board and CYPCN cancer meetings as appropriate.	2.3 Detailed in job plan.
2.4 A lead consultant and nurse for each of the PTC and the POSCUs will be confirmed by the CYPCN in consultation with their respective CLC and Medical Director or Executive Lead.	2.4 Documentation to be provided by the CYPCN.
2.5 The PTC MDT lead clinician will: a have overall responsibility for team working, the team meeting and clinical audit; b ensure that all children have a written care/treatment plan; c ensure that every child cared for under the shared care arrangements will have a named lead clinician at the PTC responsible for directing the supervising treatment and liaising with each POSCU and a named lead clinician at the POSCU; d ensure 24-hour telephone advice is available for clinicians	2.5 Responsibility detailed in job plan with evidence provided of: a regular team meetings with attendance register and evidence of clinical audit undertaken; b PTC lead clinician's responsibilities regarding monitoring shared care arrangements; c service modernisation e.g. process mapping and capacity/demand studies; d dedicated administrative and secretarial support; e attendance at Health Board/Trust and CYPCN meetings.

from a named specialist from the PTC; e provide clinical advice and co-ordinate any modernisation projects that are associated with working of the MDT; f have dedicated administrative and secretarial assistance to support the functioning of the MDT; g attend both Health Board/Trust and CYPCN meetings as appropriate.	
2.6 The POSCU MDT lead clinician will: a have responsibility for the quality of care provide by the POSCU and operational liaison with the PTC; b ensure a named key worker and specialist clinician is responsible for co-ordinating the care of each child and for communicating with other members of the POSCU MDT, primary care team and PTC; c have dedicated administrative and secretarial assistance to support the role and attend CYPCN meetings and Health Board/Trust meetings as appropriate.	2.6 Requirements to be detailed in job plan.
2.7 Each CYPCN will adopt a process, utilising the national self assessment tool, by which the Health Board Cancer Management Team hosting the PTC and linked POSCUs report to their Health Boards/Trust Boards at least annually on compliance with the National Standards for Children and Young People with cancer.	2.7 a Outline of process for annual assessment. B Minutes of Health Board/Trust board meetings covering the annual report on compliance to the standards.
2.8 An analysis of the reasons	2.8 Health Boards/Trust to

for non-compliance with standards is undertaken with action plans, agreed by the CYPCN and WHSSC drawn up as a result.	provide documentation of agreed action plans.

Topic: Patient-centered care

Objective 3: To ensure that patients and/or their carers have support and all the information they require regarding the diagnosis, treatment options and treatment care plan.

Rational: Appropriate information whether provided in written form or via face-to-face communication is required to support children and their families/carers throughout the cancer journey. All healthcare professionals need to e sensitive to potential problems with communication, with information being tailored to the needs of individual patients. Parents and children need appropriate information to make informed choices about treatment. Children benefit from age specific information in order to participate in these choices. Special training can improve communication skills in general and will provide for effective communication of the diagnosis, treatment options and treatment care plan.

The psychological needs of children and their families are often not addressed and, when facing the diagnosis of initial or recurrent cancer in a child, may benefit from specific psychological or psychiatric therapy. The input of psychological support cannot be underestimated.

It is also recognised, and is an existing requirement that accommodation for parents/families is required to enable them to be near their child during treatment.

Standard	Examples of monitoring criteria
3.1 The PTC and POSCU MDTs will agree a communication policy regarding: a communication of agreed essential information between the PTC and POSCU teams; b communication between	3.1 Detail of MDTs communication policies to include: a detail of agreed essential information and timescale that is to be communicated between PTC and POSCU MDTs;

members of the team; c communication between the team members and the patient and their carers; d communication skills training for team members with direct patient contact especially those involved in breaking bad news; e adequate time for patients to consider treatment options.	b audit of time taken for the management plan agreed at the MDT to reach the POSCU with action/s taken where this has been achieved within the required timeframe; c evidence of communication skills assessment; d evidence that the MDT has considered the views of its patients or carers regarding the appropriateness of communication.
3.2 Written information in a language and format appropriate to the patient will be offered to the parents of each new cancer patient with age-specific information for the child. This should include: a general background information about the specific cancer; b detail of treatment options, specific local arrangements including information about the MDT and support services and whom the patient should contact if necessary; c details of local self-help/support groups and other appropriate if necessary; d information about long-term follow up and possible sequelae.	3.2 Copies of examples of the documentation provided to patients/carers to be provided to the Cancer Network Director.
3.3 Each PTC and linked POSCU will nominate a person with sufficient cover to be responsible for ensuring written information is offered to all new patients	3.3 Name of responsible person and detail of provision of written information within the communication policy.
3.4 The LHB should ensure all communication with patients with special needs in relation to	3.4 Detail audit of LHB communication Policy.

language, culture and physical learning disability is addressed.	
3.5 There is access to a private room or area where patients and/or their carers can discuss the diagnosis in conditions of adequate privacy with the appropriate member of the MDT.	3.5 Details should be provided of facilities available.
3.6 The MDT responsible for each stage of a patient's care will ensure that patients are assessed for ongoing support needs including assessment of psychological support for painful procedures and following treatment for cancer.	3.6 MDT operating policy to include assessment for psychosocial support at: a diagnois; b during treatment; c end of definitive treatment; d during long-term follow-up; e at relapse; f during palliative care; g at bereavement.
3.7 A benefits/welfare rights specialist provides benefit advice to children and young people and their families at diagnosis of cancer.	3.7 CYPCN to detail access to benefits/welfare rights specialist.
3.8 Children and their families found to have significant levels of anxiety or depression will be offered prompt access to specialist psychological support or psychiatric care capable of providing level 3 and level 4 psychological interventions as defined in the NICE Supportive and Palliative Care Guidance.	3.8 CYPCN to detail access arrangements.
3.9 The CYPCN will facilitate a Network-wide approach to psychological support services as recommended in the NICE Supportive and Palliative Care Guidance.	3.9 CYPCN to detail access.
3.10 A summary of treatment received, complications experienced and existing or anticipated late effects should be	3.10 Audit to confirm that treatment summaries are provided on discharge after initial treatment.

made available to the patient and/or parents and health care professions.	

Topic: Multidisciplinary Team

Objective 4: To ensure that cancer care for children is provided by a specialist multidisciplinary team.

Rational: Patient care needs to be provided by an appropriate team of specialists to ensure high quality care that is based on a range of expertise within different specialities. For children, the diagnosis of cancer will be made or confirmed and the subsequent treatment plan directed by the PTC working in partnership with POSCUs. The team will vary as the patient moves through the care pathway from diagnosis and treatment through to follow up and this is reflected in the following standards. Standards setting out the requirements for communication between clinical teams are covered under Objective 2. Requirements in relation to the management of the 'late' effects that may impact on children and young people where cure or remission has been achieved are covered under Objective 12.

Team working will support cover for annual leave, sick leave and holidays and will enable the MDT to function at all times. Team membership will need to be reviewed to ensure appropriate input into the management of patients and to reflect new roles such as advanced practitioners as they become established.

A programme of audit, defining performance against the cancer standards will provide the Cancer Networks, MDTs, Health Boards/Trust, WHSSC, the public, and the Welsh Assembly Government with the information needed to maintain and improve cancer services. Identifying and rewarding areas of strength are important for morale and motivation. By developing an effective audit programme, Networks and MDTs can also define whether any weaknesses are due to organisation factors or to resource issues, a distinction that is of the utmost importance in seeking the appropriate remedy.

Standard	Examples of monitoring criteria
4.1 All clinicians treating children with cancer aged up to	4.1 Evidence to be provided as part of annual audit by the

and including 25 years will be part of the CYPCN and based in a designated PTC or a linked POSCU to ensure that diagnosis, treatment and patient management decisions are taken on an MDT basis.	CYPCN.
4.2 Paediatric oncologists and haematologists will be members of the CCLG. Core membership of the PTC diagnostic and treatment MDTs will include at least two of each of the following specialties; there should be a minimum of five paediatric haematologists/oncologists. Core members of the diagnostic and treatment MDT: a paediatric oncologists with responsibility for solid tumours; b paediatric haematologists with responsibility for haematological malignancy; c clinical oncologists with subspecialisation in paediatric radiotherapy; d paediatric radiologist; e paediatric surgeon with an expertise in specialist oncology; f pathologist/cytogeneticist; g MDT co-ordinator. Paediatric specialist personnel on site: h anaesthetics; i radiology, pathology/cytogenetics j oncology pharmacist; k nursing establishment in line with royal College of Nursing Guidance; l designated oncology pharmacist;	4.2 a detail membership of the CCLG; b detail names and designated time of diagnostic MDT members including documentation confirming sessional commitment by clinicians and cancer specific post-registration qualifications of team members; c detail arrangements for co-ordination secretarial support; d detail arrangements to ensure that cover is provided when individual MDT members are absent.

m designated lead for psychological and psychiatric services; n designated social workers; o research nurse; p data managers; q identified lead nurse; r specialist trained nurses for ward and day care; s oncology outreach nurses; Core Allied Health Professionals: t paediatric dieticians; u paediatric physiotherapists; v paediatric occupational therapists; w play therapists.	
4.3 The PTC will have immediate access to the following: a paediatric intensive care; b paediatric anaesthetics with 24 hour cover; c paediatric neurosurgical services; d paediatric radiology; e paediatric respiratory physiotherapy; f other tertiary services (cardiology, renal, endocrinology, nuclear medicine, other specialised surgical services); g dental services; h Pain management teams; i palliative care teams.	4.3 PTC to detail access arrangements.
4.4 The PTC MDT will have access to the following specialist services on site: a paediatric anaesthetics; b paediatric radiology; c paediatric pathology/cytogenetics;	4.4 The PTC to detail access to on-site services.

d designated theatre lists; e designated oncology pharmacist; f designated lead for psychological and psychiatric services.	
4.5 There should be an on-call 24/7 rota for the PTC which is staffed wholly by consultants each of whom is a paediatric oncologist or haematologist providing in-patient care as part of their timetable during normal working hours. The on-call consultant should provide advice regarding children with cancer being managed anywhere in the CYPCN.	4.5 Detail on-call arrangements and protocol for provision of on-call support to patients being managed within the CYPCN.
4.6 The late effects MDT responsible for the management of patients once the initial treatment has been completed will include the following members of this team being identified as the key worker for each patient: a lead clinician (oncologist with expertise in late effects with specific direct clinical care sessions in their job plan dedicated to the work of the late effects MDT; b specialist nurse; c endocrinologist; d allied health professional; e psychological services professional.	4.6 Detail names of designated MDT members, sessional commitment as outlined and specific training undertaken regarding the management of late effects.
4.7 The POSCU MDT will include the following members: a leadpaediatrician/ oncologist/haematologist; b key worker; c designated lead nurse and ward nurse;	4.7 a detail names and designated time of MDT members including documentation confirming sessional commitment by clinicians and cancer specific post-registration qualifications of

d paediatric oncology outreach nurse; e pharmacist; f ward nurse; g allied health professionals; h social worker.	team members; b detail arrangements for co-ordination and secretarial support; c detail arrangements to ensure that cover is provided when individual MDT members are absent.
4.8 The PTC diagnostic and PTC treatment MDT meetings should each be held every week and should review all new cancer patients. Core members should attend at least 50% of the MDT meetings. The MDT will follow an agreed policy for review of the management of all patients currently undergoing treatment or supportive care regardless of the setting. Where inpatients treatment and care is being delivered daily team assessment of patients should be in evidence.	4.8 a detail meetings help and % attendance of team members; b audit of MDT discussion of management plan in patient notes.
4.9 The PTC diagnostic and treatment MDT will ensure a key worker is identified for each patient at each stage in their care pathway.	4.9 Evidence from case notes of named key worker.
4.10 All MDTs within the CUPCN should ensure that all relevant sections of the All Wales Cancer Data Set are completed for each new patient diagnosed with a malignancy.	4.10 Detail a number of new malignant cancer cases referred to the team per year and recorded on the All Wales Cancer Data Set; b detail the number of referrals on to specialist transplantation MDTs (>2BCSH); c % Completion of the core All Wales Data Set.
4.11 All MDTs within the CYPCN will participate in UK-wide/national clinical audit as specified by the CYPCN Advisory Group.	4.11 Clinical Network annual report to detail Network-wide audit programmes and resulting action plans.

4.12 LHBs/Trusts should ensure that the expected registration of incidence using the Patient Episode Database for Wales (PEDW) data is submitted to the Welsh Cancer Intelligence and Surveillance Unit (WCISU) within 3 months of calendar year end.	4.12 WCISU to monitor registrations received against expected registrations (based on an average of the lst 3 years registration per Trust).

Topic: Initial referral and times to treatment

Objective 5: Children with cancer should be referred, diagnosed and treated in a timely, appropriate fashion.

Rationale: The majority of children with acute or rapidly progressing disease will require prompt diagnosis and treatment. Initially efforts have been directed to ensure that patients referred urgently with suspected cancer are offered an appointment with a member of the MDT within 10 working days. This has now been extended to ensure that patients with acute or rapidly progressing disease are not only seen promptly but also complete diagnostic investigations and start treatment within an accepted timeframe that applies generally to all cancers. Shorter waiting times are required for specific cancers where clinically indicated and this is the case for children with cancer where aggressive cancers require start of treatment as soon as possible and always within one month of receipt of the referral at the hospital. For certain types of cancer the definitive treatment policy is initial surveillance with specific anticancer therapy deferred until such time as it is clinically indicated.

Children may develop a clinical problem while out of hospital at any time e.g. neutropenic fever/haemorrhage. It is therefore essential that children and their carers have immediate access to the MDT managing their care for advice or treatment.

Standard	Examples of monitoring criteria
5.1 The CYPCN will agree referral guidelines for use by the PTC diagnostic and treatment MDT that are in accordance with NICE referral guidelines for suspected cancer.	5.1 a Confirmation from the CYPCN that all local General Practitioners (GPs) in the area have a copy of referral

	guidelines. B Audit of referrals to confirm that guidelines are being followed.
5.2 Written referral pathways are drawn up by the CYPCN which details the patient journey from whichever poin patients access the system across the network.	5.2 Confirmation that the CYPCN lead clinician has a copy of agree pathways.
5.3 The CYPCN should ensure that referral pathways are adhered to particularly where pathways cross Health Board/Trust or Network boundaries.	5.3 Networks to provide evidence of review of agreed referral pathways.
5.4 A pathway agreed by the CYPCN is in place for dealing with suspicious lumps and inconclusive scans.	5.4 CYPCN to confirm pathway is in place and provide details of pathway.
5.5 Children presenting to their GP with symptoms with the criteria for suspected should be referred as 'urgent suspected cancer' to the PTC.	5.5 Audit of referral process.
5.6 The GP will be informed if the specialist downgrades an urgent suspected cancer referral to non-urgent.	5.6 Audit of downgraded referrals.
5.7 Confirmation of the diagnosis of malignancy should reach the GP from the PTC MDT by the end of the next working day after the patient/family has been informed.	5.7 Audit of proportion of patients diagnosed with cancer where information was sent to the GP within the required timescale.
5.8 Patients referred as urgent suspected cancer by the GP and confirmed as urgent by a member of the PTC MDT or their representative should, if diagnosed with a malignancy, start definitive treatment within 31 days of receipt of referral at	5.8 Waiting times from receipt of 'urgent suspected cancer' referrals to start of definitive treatment.

the hospital.	
5.9 When diagnosed with a cancer, patients not already included as an urgent suspected cancer referral from primary care should start definitive treatment within 1 month from diagnosis regardless of referral route.	5.9 Waiting times from diagnosis to start of definitive treatment.
5.10 Where initial referral has been made to a clinician who is not part of the PTC MDT, a process is in place for prompt referral to the PTC MDT.	5.10 Policies in place and audit of adherence undertaken.
5.11 Where patients are initially referred to a POSCU, the referring clinician will inform the parents/carers with parental responsibility of the possibility of a diagnosis of cancer prior to transfer to the PTC.	5.11 Evidence of formalised managerial and clinical links between the haematology units and specialist/designated centres.
5.12 There should be explicit arrangements for referral to centres for radiotherapy, bone marrow/stem cell harvesting and transplantation as agreed by the PTC. Referral pathways should be identified for stem cell transplantation. Clinical and managerial links should be in place between the referring unit and the specialist centre.	5.12 Evidence of formalised managerial and clinical links between the haematology units and specialist/designated centres.
5.13 Patients undergoing radiotherapy should be treated within the maximum waiting times as recommended by the Joint Council for Clinical Oncology (JCCO).	5.13 Waiting times from receipt of the request form by the radiotherapy department, or verbal request, to the date of the first radiotherapy fraction.
5.14 High dose therapy with progenitor cell transplantation will be carried out only in	5.14 a details of activity and facilities

centres that meet the Joint Accreditation Committee ISCT-EBMT (JACIE) accreditation standards and carry out the minimum number of autologous and/or allogeneic stem cell transplant procedures per year. MDTs undertaking fewer transplant procedures should only do so in agreement with the CYPCN and must be able to demonstrate adequate staffing, facilities, management according to clinical protocols. In addition the unit should demonstrate a clinical and managerial relationship with larger accredited transplantation centre.	in relation to JACIE standards; b CYPCN to provide documentation confirming support of MDTs if treating less than recommended transplant procedures per year.
5.15 There is access to specialist surgical treatment for very rare paediatric cancers or tumours that occur more commonly in adults. Referral pathways are co-ordinated by the designated PTC MDT and will include: a retinoblastoma; b bone tumours; c liver tumours; d non-rhabdomosarcoma/soft tissues sarcoma.	5.15 Evidence of referral pathways and links between specialist/designated centres.
5.16 Children with CNS tumours will receive their care in a dedicated children's neurosurgery centre.	5.16 Evidence of referral pathway.
5.17 A referral pathway will detail access to neuro-rehabilitation services for children and young people with CNS malignancy.	5.17 Referral pathway in place.
5.18 For patients referred initially to a POSCU, a process	5.18 Evidence of referral pathway, and audit of patient

will be in place to ensure rapid communication between the lead clinician at the POSCU and at the PTC regarding management of the patient once a cancer is suspected.	management plan.
5.19 Where cancer is suspected, transfer from the POSCU to the PTC should not be delayed however complex imaging may be undertaken at the POSCU if agreed with the PTC lead clinician that this will expedite the diagnostic process.	5.19 Audit of patient management plans.
5.20 Treatment may be initiated at the POSCU in exceptional circumstances and only with agreement of the PTC where it is in the best interest of the patient.	5.20 Audit of patient management plans.

Topic: Diagnosis, staging and treatment

Objective 6: Children with cancer should be diagnosed, staged and treated promptly and in-line with best practice guidelines.

Rationale: It has been accepted that patients treated within a trial setting fare better than those treated outside of a trial setting, and this is thought to be due in large measure to the benefits of treatment according to documented protocols, with details of action to be taken in case of adverse effects, dose escalation etc. Standardisation of referral pathways and clinical protocols across the CYPCN will enable outcome assessment to be performed in a uniform manner, and staff gain greater expertise by concentrating on a lesser number of well-defined protocols.

Post treatment rehabilitation, tailored to the individual needs, is essential to achieve the best outcomes for each child and young person. Standard 6.1 sets out the requirements for the clinical management of patients and includes follow-up and rehabilitation. In addition, Standards 5.17 and 6.3 specifically focus on issues relating to children and young people with CNS tumours.

Standard	Examples of monitoring criteria
6.1 Clinical management of patients including follow-up should follow written locally agreed clinical policies, in-line with NICE service guidance and clinical guidelines when published. These clinical policies are developed by the PTC and should include management of: a febrile neutropenia; b raised intra cranial pressure; c central venous access; d nausea/vomiting and bowel disturbance; e use of blood products; f pain g oral and dental care; h rehabilitation; i psychosocial care.	6.1 Documentation detailing: a the agreed clinical policies; b evidence from clinical audit that policies are followed.
6.2 Psychological or behavioural therapy is available to children anticipatory nausea and vomiting.	6.2 Evidence of availability of appropriate service.
6.3 The PTC will ensure cognitive assessment is available via neuropsychology services for children with CNS tumours.	6.3 Evidence from clinical audit that cognitive assessment is undertaken.
6.4 The PTC will refer on patients with a suspected liver/bone sarcoma or retinoblastoma to an appropriate specialist centre that complies with NICE service guidance.	6.4 Documentation to provide evidence that specialist centres are designated by WHSSC to be meeting the NICE service guidance and are participating in local and national clinical audit.
6.5 Patients diagnosed with leukaemia and being treated in hospitals providing a service level > 1 (BCSH Guidelines) must have emergency access to the treating MDT.	6.5 Detail arrangements for patient access to the treating MDT at any time in the case of an emergency.
6.6 General anaesthesia is readily accessible if require dfor	6.6 Audit documentation.

patients undergoing regular painful procedures and screening investigations.	
6.7 The PTC ensures all patients are given the opportunity to enter approved clinical trials for which they fulfil the entry criteria.	6.7 The team to provide documentation of all open tirals and numbers of patients entered per trial per year.

Objective 7: The MDT should have access to high quality imaging services.

Rationale: Imaging is important in the diagnosis and staging of many patients with cancer. Waits for imaging investigations may introduce significant delays before clinical diagnosis is confirmed and appropriate treatment can be instituted. This is particularly true for complex investigations.

Imaging departments need to work to high standards of service delivery that encompass management systems, waiting list management, procedural work, examination reporting, provision of clinical advice and quality assurance.

In order to achieve this, initial work is required to unify imaging protocols and staging reports between different hospitals. This will avoid additional unnecessary studies and make clinically meaningful comparison and review of services and outcomes possible.

Standard	Examples of monitoring criteria
7.1 Imaging departments should provide clear, written information to its Clinical Networks(s) on the range of investigations provided, and their availability. Where availability is limited or intermittent, particularly for complex investigations, there should be written alternative referral pathways agreed with the CYPCN.	7.1 Copy of documentation to be provided by the appropriate clinical head of imaging.
7.2 Standardised imaging	7.2 The PTC to have copies of

protocols for staging should be agreed with the CYPCN.	standarised protocols for staging. Local copies of documentation to be provided by the appropriate clinical lead of imaging services.
7.3 Staging should be reported in a standarised format agreed within the CYPCN.	7.3 Evidence of adherence to the standarised format to be held by the PTC Manager.
7.4 All reports should, as a minimum, allow assessment of that component of TNM status which relies on diagnostic radiology.	7.4 Clinical audit of assessment and recording of stage.
7.5 For children where a diagnosis of suspected cancer has been made outside the PTC, digital or hard copy of relevant images will be forwarded to the PTC at or prior to transfer.	7.5 Evidence from audit that relevant images are transferred to the PTC at or before transfer of the child to the centre.

Objective 8: The MDT should have access to high quality pathology services.

Rationale: Pathology laboratories should work to high standards of service delivery that encompass management systems, diagnosis, specimen reporting, provision of clinical advice and quality assurance.

Adequate and appropriate information in pathology reports is essential to inform prognosis, plan individual patient treatment, support epidemiology and research and to evaluate clinical services and support clinical governance. Specialist histopathologists should be members of relevant specialists UK and participate in the relevant specialised national External Quality Assessment (EQA) scheme. Diagnosis of sarcoma and lymphoma is complex and good practice guidance supports the use of specialist histological review of cases at Principal Treatment Centres.

Standard	Examples of monitoring criteria
8.1 All pathology laboratories within the CYPCN should	8.1 Certificates of participation in EQA/CPA.

participate in Technical EQA and Clinical Pathology Accreditation (CPA)	
8.2 All histopathologists reporting malignancies should participate in a national paediatric pathology EQA scheme.	8.2 Certificate of participation of all pathologists who report paediatric malignancies in an appropriate diagnostic EQA scheme.
8.3 Each PTC treatment children has access to designated specialist paediatric and tumour specific pathologists, immunohistochemistry and spinal fluid cytology.	8.3 Detail specialist services used.
8.4 Specialised techniques in immunohistochemistry, spinal fluid cytology molecular diagnostics and cytogenetics should be integrated with morphological diagnosis.	8.4 Detail arrangements for access to specialised techniques and their integration with conventional morphological diagnosis.
8.5 Tumour banking facilities are available for tissue/cell/ CAN storage.	8.5 Detail arrangements with the Wales Cancer Bank.
8.6 A paediatric haematologist is directly involved in the laboratory and clinical management of children with leukaemia and those undergoing haemopoetic stem cell transplantation (HSCT).	8.6 Audit to confirm that all diagnosis of leukaemia is signed off by a paediatric haematologist.
8.7 A pathway is in place for urgent review of suspected sarcoma (non Rhabdomyosarcoma) pathology specimens by a paediatric or specialist sarcoma pathologist who is a member of a designated sarcoma treatment centre.	8.7 Evidence of agree pathway.
8.8 For children where a diagnosis of suspected cancer has been made outside the PTC all tissue samples will be	8.8 Audit of whether tissue samples were forwarded at or prior to transfer.

forwarded to the PTC at or prior to transfer.	

Objective 9: To ensure surgery is undertaken by specialists with appropriate expertise.

Rationale: the majority of diagnostic and surgical procedures required for the investigation and treatment of children with cancer general anaesthesia. The need for these procedures is usually urgent but not necessary an emergency. The provision of sufficient planned surgical lists with paediatric anaesthetic cover is therefore necessary to provide a timely service provided by clinicians with recognised expertise for the diagnosis and surgical treatment (as appropriate) of cancer in children.

The majority of children will require central venous access via a Hickman line or portacath and the timely insertion of these catheters by experienced surgeons is also important.

Standard	Examples of monitoring criteria
9.1 Named consultant paediatric anaesthetists with direct clinical core activities in their job plan, designated for children's cancer diagnostic and surgical procedures.	9.1 Names of paediatric anaesthetists and number of agreed sessions within job plan.
9.2 Specified sessions of paediatric ODA time for Children's diagnostic and surgical procedures.	9.2 The sessions agreed by the Head of Service and the relevant Hospital manager.
9.3 Paediatric oncology surgery should be provided by at least two designated and accredited paediatric surgeons in each PTC. At least one of these two surgeons should be a member of both the Surgical Working Group of the CCLG and have formal sessional commitment to multidisciplinary (MDT) oncology work. This is defined, in this context, as clinical meetings with paediatric oncology/haematology/radiotherapy colleagues; histopathology and	9.3 a review of the Specialist Register of the GMC; b the membership list of the Surgical Working Group of the CCLG; c individual job plans; d registers of attendees at clinical, histopathological & radiological MDTs, patients notes.

radiology meetings relating to paediatric oncology; joint ward rounds; joint consultations over specific patients.	
9.4 The designated oncology surgeons should share the paediatric oncology surgery (defined as tumour resection, biopsy, venous access, staging and other tumour-specific procedures), and assist each other in major cases.	9.4 Evidence from records of routine operating lists to ensure that the work is being divided; and the operating notes of major cases, to establish hen both surgeons attended.
9.5 Oncology surgery (defined above) should be performed on elective lists wherever practicable, and all should either be performed or supervised by one of the designated oncology surgeons.	9.5 Audit of surgery undertaken 'out of hours' and who performed it.
9.6 There should be weekly elective operating time or elective radiology time for venous access and biopsies.	9.6 a Evidence of weekely elective operating lists in the theatre/operating list records or evidence of weekly elective arrangements for venous access should be ascertained from radiology records. B Audit of timely procedures by review of patients' notes.
9.7 The correct position of all central venous catheters must be checked after insertion whilst the child is still on the operating table, preferably by fluoroscopy; this suitable radiography support in theatre must be available for the procedure.	9.7 Audit of the operating notes to confirm that correct positioning of central venous catheters was routinely confirmed.
9.8 All biopsies and resected primary tumours must be sent to the laboratory fresh, and processed appropriately and in a timely fashion.	9.8 An audit of the pathology reports to confirm receipt of fresh tissue; and review of the laboratory policy for the processing of unfixed

	specimens.
9.9 Results of major tumour resections over a five-year period to be consistent with reasonable standard set by the Surgical Working Group of the CCLG.	9.9 Audit by SWG; cross-referenced where appropriate with surgical trial forms.
9.10 Results and complication rate of venous access procedures to be consistent with the standard set by the Surgical Working Group of the CCLG.	9.10 Evidence from clinical audit.
9.11 Both nominated surgeons to undertake at least 12 hours CPD per year relating specifically to paediatric surgical oncology.	9.11 Evidence from annual appraisal.

Objective 10: To ensure patients receive radiotherapy which is planned, prescribed, delivered and supervised in a safe and effective manner.

Rationale: Radiotherapy is an important part of the management of many children and young people with cancer. In relation to brain tumours, accuracy of radiotherapy relates to tumour control with associated avoidance of unnecessary irradiation to normal brain minimising late neuro-cognitive effects.

It is essential that the patient remains still, sometimes for up to 25 minutes, during treatment with radiotherapy. Thus, there are particular challenges in treating infants and young children, who may need to be anaesthetised for their treatment.

As curative radiotherapy commonly requires daily treatment for several weeks, appropriate anaesthetic skills and support need to be easily available. Play therapy is vital in helping young children through this process and may prevent the need for anaesthesia.

Therapeutic radiographers with specific training in the management of children are needed to provide safe and efficient care during radiotherapy through their specialist, detailed knowledge of the planning, delivery and anticipated side effects of radiotherapy. They also enable maintenance of continuity of care during the planning and treatment period for the child and family.

As with other forms of treatment, the results of radiotherapy are likely to be optimum when it is delivered according to a formal written policy specifying dose, fractionation, over treatment time, planning technique and means of verification plus other appropriate QA measures. This is especially true of radical (curative) therapy, where a uniform approach is necessary to be able to evaluate outcomes. It is also important that policies are in line with those in use elsewhere in the UK and worldwide. Where there is substantial deviation, this should be in the context of a formal clinical trial. Palliative treatments will need to be individualised on a more frequent basis, but the overall approach should conform as closely as possible to a written policy.

There are circumstances where evidence exists for the superiority of one form of technology over another. An example is the use of conformal radiotherapy in some pelvic malignancies, as a means of reducing treatment-related side effects. Networks need to have a strategy to ensure that patients for whom such technology is optimum are able to access it, even if this means crossing Health Board/Trust or Network boundaries. In certain cases, for example proton therapy, new technologies may not be available in the UK and a collaborative equitable approach is recommended. The Department of Health have established a UK referral panel to manage the referral of appropriate children for proton therapy abroad until such time as a facility is available in the UK.

The general quality of procedures in radiotherapy department will be reflected in externally modulated quality schemes as originally specified by Quality Assurance in Radiotherapy (QART).

Standard	Examples of monitoring criteria
10.1 Radical radiotherapy will be undertaken at a radiotherapy centre undertaking paediatric radiotherapy either at or in close collaboration with the PTC.	10.1 Detail arrangements for paediatric radiotherapy.
10.2 Facilities at radiotherapy centres for children include: a access to paediatric anaesthetists, operating department assistants and	10.2 Centres providing paediatric radiotherapy to provide evidence that they comply with requirements a) to e).

nurses with paediatric recovery training, with modern facilities including full resuscitation and recovery area on site; b policies and procedures for the safe supervision of children receiving sedation and anaesthesia; c clinical protocols agreed with the PTC; d a lead therapeutic radiographer with specific training and responsibility for treating children and young people; e age-appropriate support facilities and staff with appropriate training for this specialised field. This will include support of play specialists.	
10.3 Clinical oncologists working in a POSCU may undertake radiotherapy only in certain circumstances under conditions of strict collaboration with the PTC.	10.3 The PTC to have a written protocol in use that is detailed within the working arrangements with each POSCU.
10.4 Children and young people receiving radiotherapy should be treated according to an agreed, documented policy or in a formal clinical trial.	10.4 a radiotherapy centres to have written clinical policies available; b clinical audit of compliance to policies to be undertaken; c deviations from the policy to be documented.
10.5 Major long-term morbidity rates following radical radiotherapy should be monitored and use nationally agreed definitions.	10.5 a audits of radiotherapy-related major morbidity by cancer; b results of audit in relation to children to be sent to the PTC.
10.6 All radiotherapy centres should have a recognised quality	10.6 Documentation of accreditation certifications.

system accredited by an authorised standards institution to a recognised standard.	
10.7 Equipment capable of delivering conformal radiotherapy should be available to each CYPCN.	10.7 a detail type and location of planning equipment; b detail type and location of multi-leaf collimator-equipped linear accelerators; c detail availability of treatment verification facilities; d accreditation certiciation.
10.8 Equipment capable of delivering Intensity Modulated Radiotherapy (IMRT) should be available to each Network.	10.8 Documentation of implementation of/or plans to implement IMRT.
10.9 There is access to highly specialised radiotherapy interventions at designated supra-regional centres for: a total body irradiation JACIE accredited centres; b irradiation for infants with retinoblastoma; c biological targeted radioisotope treatments; d brachytherapy; e radiosurgery; f hypofractionated stereotactically guided radiotherapy.	10.9 The paediatric radiotherapy centre to detail access to the required highly specialised interventions.
10.10 Paediatric radiotherapy centres should collaborate with the national referral panel to provide access to proton therapy for children meeting the referral criteria.	10.10 The WHSSC to confirm collaboration between the paediatric radiotherapy centres and the national referral panel to provide proton therapy.

Objective 11: To ensure patients receive chemotherapy which is planned, prescribed, delivered and supervised in a safe and effective manner.

Rationale: As with all other forms of treatment, the results of chemotherapy are likely to be optimum when it is delivered according to a formal written policy. It is also important that policies are in-line with those in use elsewhere in the UK and worldwide. Where there is substantial deviation, this should be in the context of a formal clinical trial.

Chemotherapeutic agents include other complex, systemic therapies such as biological agents and cytokines. Chemotherapeutic agents are potentially dangerous and fatalities have occurred due to the inappropriate administration of some chemotherapeutic agents via the intrathecal route. It is therefore essential that chemotherapy is provided by trained specialist staff in a safe environment with appropriate facilities. Standardisation of protocols across the CYPCN will enable outcome assessment to be performed in a uniform manner; and staff gain greater expertise by concentrating on a lesser number of well-defined protocols.

Parts of some treatment regimens can be safely delivered at home. Where this has been risk assessed and found to be a safe option whether administered by appropriately trained community nurses, other health professionals or families this should be supported and adequately resourced.

Standard	Examples of monitoring criteria
11.1 There should be an overarching chemotherapy policy applicable to all providers of chemotherapy within each Health Board, that is compatible with any guidance from NICE or The Joint Council for Clinical Oncology (JCCO), covering generic issues pertinent to chemotherapy: a staff (all involves in prescription, dispensing and administration of chemotherapy) grading, training and competencies; b prescribing;	11.1 Documentation of the Health Board chemotherapy policy detailing the following: a staff authorised to initiate chemotherapy; b documentation of the on-site facilities for the preparation of chemotherapy and of compliance with NHS standards for aseptic preparation; c job description of designated pharmacist responsible for overseeing pharmacy services to the ward/out-patient area where chemotherapy is administered; d facilities for the administration

c preparation and dispensing; d administration; e disposal of waste and spillage.	of chemotherapy plus any dedicated areas for administration of intrathecal chemotherapy if this is undertaken. To include details of policies and equipmnent for the administration of chemotherapy plus the management of emergencies such as anaphylaxis, extravasation, spillage of cytotoxics and cardiac arrest; e training and post-registration qualifications of chemotherapy nurses; f confirmation that the Health Board chemotherapy policy is available in all areas where chemotherapy is administered.
11.2 Detailed written chemotherapy protocols should be developed by the PTC. These protocols should include: a regimen/s and their indication; b drug doses and scheduling; c pre and post-treatment investigations; d dose modifications.	11.2 Detail of PTC chemotherapy protocols by cancer site.
11.3 Intrathecal chemotherapy should be controlled by a process that ensures that it is only prepared, handled and admisistered by suitable trained personnel who appear on the intrathecal chemotherapy register for that site and adheres to Welsh intrathecal guidelines.	11.3 Annual monitoring by All Wales Principal Pharmacist Quality Control.
11.4 Major morbidity following chemotherapy in patients treated with curative intent should be monitored.	11.4 Audits of chemotherapy-related major morbidity for patients treated with curative intent by cancer.
11.5 Where the PTC considered	11.5 PTC to have written policy

it safe for a child to have elements of their chemotherapy treatment at home, they must ensure it is administered by/supported by trained staff.	in place that details the requirements for delivery of chemotherapy at home.
11.6 All POSCU nursing and medical staff who prescribe and/or administer chemotherapy should undertake theoretical and practical skills updating, approved by the PTC, at least every three years. POSCUs should maintain records documenting staff training.	11.6 POSCU to provide documentation of staff training.
11.7 A written policy is in place stating the exceptional circumstances in which the initiation of a course of chemotherapy may be allowed outside times when the standard compliment of trained staff are on duty.	11.7 Evidenced from chemotherapy policy.
11.8 Where oral chemotherapy is given by parents there should be confirmation of appropriate education and documented competency.	11.8 Audit to confirm education and competency.

Topic: Diagnosis, staging and treatment

Objective 12: To ensure that all children and young people receive adequate long term follow up care.

Rationale: With increasing survival, the physical, emotional and social sequelae, which may impair the quality of life in the long term, because more important. Although many of those cured of cancer during childhood or young adulthood will return to good health, others will experience significant late sequelae. Objectives 3 and 4 also include standards that address issues in relation to late effects and should be read alongside the additional standards outlined here.

Sequelae can occur at any time during or following completion of therapy. They include problems such as impairment of endocrine function (for some including infertility, abnormal growth and development or bone mineral accretion), cardiac and neurological impairment, cognitive decline (for example, following treatment for tumours of the CNS) and psychological effects. It should be recognised that children may have problems with learning because of schooling missed as a result of treatment and longer term cognitive disability for example following radiotherapy for brain cancer. Some patients may have significant disability for example loss of limb or sight.

There is also an increased risk of developing a second cancer in some patients. On average, 4% of childhood cancer survivors develop a second primary malignancy within 25 years of diagnosis although for certain diagnoses this figure is higher. Radiotherapy is a particular risk factor. The risk of second malignancy, which can occur many years after the primary diagnosis, is estimated to be between four and six times the risk in the general population.

Because patients experiencing late effects are likely to present first to a GP and not to those involved in their original treatment, continued communication with primary care is important. Referral needs to be a specialist with an understanding of the patient's previous disease and therapy. Therefore coordination and communication across MDTs and between the PTC and the POSCU are very important. Although most of the treatment needs to be given in the PTC it is expected that, wherever possible, follow-up will be delivered closer to home. Furthermore as survivors become adults they often need referral to a variety of specialists, which is much more appropriate close to the patient's home.

Standard	Examples of monitoring criteria
12.1 There should be a single late effects MDT per CYPCN responsible for ensuring surveillance processes are in place for all children who are cancer survivors.	12.1 The late effects MDT to provide evidence of numbers of patients managed and catchment population served. Details of surveillance policy to be provided to the Cancer Network Director.
12.2 Where long term follow up is organised at a local level, there should be agreed	12.2 To be monitored as part of standard 3.1.

communication between the local care services and the PTC late effects team.	
12.3 Where there is a designated late effects team outside the PTC they should communicate directly with the PTC to ensure all late effects are documented.	12.3 To be monitored as part of standard 3.1.
12.4 Each long-term survivor has a named key worker.	12.4 Surveillance policy.
12.5 A care plan is developed for every long-term survivor in partnership with the child, young person and their family.	12.5 Survey of patients/carers.
12.6 Fertility advice is available to all long-term survivors.	12.6 Detail of advice service and measure of availability.

Objective 13: to ensure that all patients receive adequate assessment of, and provision for, palliative care needs at all times and in every setting. This includes care of dying patients, their families and carers.

Rationale: The palliative approach may be applicable at any stage of a patient's illness and incorporates the particular needs of the dying patient. It is the responsibility of all health professionals caring for those with progressive life-threatening disease, informed by knowledge of palliative care principles and practice and support by a specialist palliative care team.

Standard	Examples of monitoring criteria
13.1 All children have access to general services and support as outlined in the CYPSS Palliative Care standards.	13.1 To be monitored by the CYPSS.
13.2 All health professionals engaged in care of children with cancer should receive training to allow adequate assessment and delivery of general palliative care.	13.2 Details of Health Board/Trust and CYPCN arrangements for staff education and training in palliative care principles and practice.
13.3 There should be clear	13.3 Details to be provided in

arrangements to access specialist paediatric palliative care services.	PTC MDT guidelines of access arrangements to specialist palliative care as defined in the CSCG Standards for Specialist Palliative Care and CYPSSP Paediatric Palliative Care standards.
13.4 Palliative care needs should be rapidly addressed, and specialist palliative care advice available, in all settings, 24 hours a day.	13.4 Details to be provided of on-call medical services out of hours that allows: a in-patient hospital or hospice visits; b domiciliary visits; c telephone advice to other professionals; d telephone advice directly to patients or families; e other support.
13.5 An integrated system should be in place in all care settings to ensure best practice in the multi-professional care of dying patients. The All Wales Care Pathway for the Last Days of Life represents an appropriate model.	13.5 Detail in PTC MDT guidelines on use of end of life care pathway.
13.6 All profession-specific teams engaged in palliative care provision for children such as nursing, physiotherapy, occupational therapy, should have at least one member who has undergone post-registration education and training in palliative care.	13.6 Details of: a availability of post registration education and training programmes; b Health Board/Trust identification of staff training priorities in palliative care.

Glossary

BCSH	British Committee for Standards in Haematology
CCLG	Children's Cancer and Leukaemia Group
CCT	Certificates of Completion of Training
CNS	Central Nervous System
CPA	Clinical Pathology Accreditation
CPD	Continuing Professional Development
CSCG	Cancer Services Co-ordinating Group
CSG	Clinical Studies Group
CYPCAG	Childen and Young People's Specialised Services Project
CYPCN	Children and You People's Cancer Network
CYPCNG	Children and Young People's Cancer Network Group
CNSAG	Cancer National Specialist Advisory Group
DGHs	District General Hospitals
ECMC	Experimental Cancer Medicine Centre Network
EQA	External Quality Assessment
EQUA	Equality Impact Assessment
GP	General Practitioner
HLH	Haemophagocytic Lymphohistiocytosis
HSCT	Haemopoetic stem cell transplantation
IMRT	Intensity Modulated Radiotherapy
JACIE	Joint Accreditation Committee ISCT-EBMT
JCCO	The Joint Council for Clinical Oncology

LCH	Langerhans' Cell Histiocytosis
LHBs	Local Health Boards
MDT	Multi disciplinary team
NCIC-ONS	National Cancer Intelligence Centre at the Office for National Statistics.
NCRI	National Cancer Research Institute
NICE	National Institute for Health and Clinical Excellence
NIHR	National Institute for Health Research
NIHR CRN	National Institute for Health Research Clinical Research Network
PEDW	Patient Episode Database for Wales
POSCU	Paediatric Oncology Shared Care Units
PTC	Principal Treatment Centre
QART	Quality Assurance in Radiotherapy
SSCCG	South Wales Children's Cancer Co-ordinating Group
TYA's	Teenagers Young Adults
UKCCSG	UK Children's Cancer Study Group
WCISU	Welsh Cancer Intelligence and Surveilance Unit
WHSSC	Welsh Health Specialised Services Committee