Services for Children with Cancer

Commissioning Policy: SS86

December 2024
Version: 2.0

Document information	
Document purpose	Service Specification
Document name	Services for Children with Cancer
Author	NHS Wales Joint Commissioning Committee
Publication date	December 2024
Commissioning Team	Children
Target audience	Chief Executives, Medical Directors, Directors of Finance, Chief Pharmacists, Paediatric Oncologists, Paediatric Oncology Clinical Nurse Specialists Paediatricians, Cancer Co-ordinators Lead Paediatric Cancer Nurses, Allied Health Professionals, Dieticians
Description	NHS Wales will routinely commission this specialised service in accordance with the criteria described in this policy
Document No	SS86
Review Date	December 2027

Publication History

Document Updates			
Updated version No.	Revision date	Summary of Changes	Policy Group approval
1.13	August-October 2024	Policy updated following receipt of consultation comments	14/11/2024
1.14	November 2024	Further revisions following Policy Group	
1.15	November 2024	Document updated ahead of publication	

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Statement

NHS Wales Joint Commissioning Committee (NWJCC) will commission the services for children with cancer aged up to 16 years in accordance with the criteria outlined in this specification.

In creating this document NWJCC has reviewed the requirements and standards of care that are expected to deliver this service.

Welsh Language

NWJCC is committed to treating the English and Welsh languages on the basis of equality, and endeavour to ensure commissioned services meet the requirements of the legislative framework for Welsh Language, including the Welsh Language Act (1993), the Welsh Language (Wales) Measure 2011 and the Welsh Language Standards (No.7) Regulations 2018.

Where a service is provided in a private facility or in a hospital outside of Wales, the provisions of the Welsh language standards do not directly apply but in recognition of its importance to the patient experience, the referring health board should ensure that wherever possible patients have access to their preferred language.

In order to facilitate this, NWJCC is committed to working closely with providers to ensure that in the absence of a Welsh speaker, written information will be offered and people have access to either a translator or 'Language-line' if requested. Where possible, links to local teams should be maintained during the period of care.

Decarbonisation

NWJCC is committed to taking assertive action to reducing the carbon footprint through mindful commissioning activities. Where possible and taking into account each individual patient's needs, services are provided closer to home, including via digital and virtual access, with a delivery chain for service provision and associated capital that reflects the NWJCC commitment.

Disclaimer

NWJCC assumes that healthcare professionals will use their clinical judgment, knowledge and expertise when deciding whether it is appropriate to apply this document.

This document may not be clinically appropriate for use in all situations and does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian, or Local Authority.

NWJCC disclaims any responsibility for damages arising out of the use or non-use of this policy.

1. Introduction

This document has been developed as the Service Specification for the planning and delivery of services for children 0 to 15 years (up to 16th birthday) with cancer for paediatric residents in Wales. This service will only be commissioned by the NHS Wales Joint Commissioning Committee (NWJCC) and applies to residents of all seven Health Boards in Wales.

Paediatric Cancer services include the diagnosis, management and follow-up of children with cancer. Less than 1% of all cancer cases in the UK are children's cancers. The types of cancer affecting children are quite different from the cancers that affect teenagers and young adults (TYA) and TYA cancers are different again from the types of cancer that typically affect adults aged 25+.

Children's cancers are classified into 12 broad diagnostic groups (each of which can be further subdivided) according to the International Classification of Childhood Cancer, Third Edition (ICCC-3). There are UK statistics for 88 distinct diagnostic subgroups of children's cancers[1].

1.1 Incidence

The most common groups of children's cancers in the UK are leukaemias, myeloproliferative diseases, and myelodysplastic diseases (31% of cases), CNS and miscellaneous intracranial and intraspinal neoplasms (25% of cases), and lymphomas and reticuloendothelial neoplasms (10% of cases) (1997-2016) [2].

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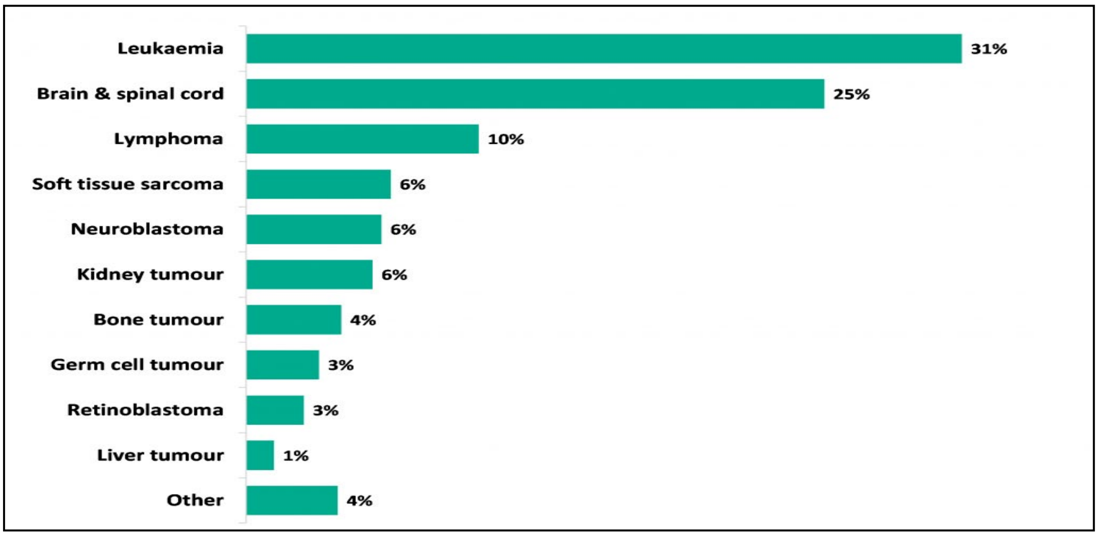
[1] Children, teenagers and young adults UK cancer statistics report 2021

[2] Children, teenagers and young adults UK cancer statistics report 2021

Figure 1: The most common cancers diagnosed in children aged 0-14 years in the UK, based on cancers registered between 1997 and 2016



For young people aged 15-24, 1 in 5 of cases are lymphomas. Around 1 in 6 are germ cell tumours, most of which are testicular cancers. Around 1 in 7 are skin cancers, 1 in 8 are brain and spinal cord tumours and 1 in 11 are leukaemia.

In Wales, an average of 202 new cases of cancer were diagnosed per year in 0-24 year olds, with 85 in 0-14 year olds and 117 in 15-24 year olds in the period from 1997-2016.

Cancer is more common in young males. Around 1 in every 420 boys under the age of 15 developed cancer compared to 1 in 490 girls in the period from 1997-2016. For young people aged 15-24, it was 1 in every 360 for males and 1 in 380 for females. For both males and females, cancer incidence is higher in the first five years of life, falls to its lowest rate at age 5 to 9 years, and then starts to increase again from 10 years of age marking the start of an unbroken rise in incidence that continues into the teenage years and throughout adulthood.

More than eight out of ten young people diagnosed with cancer survive at least five years, and many of these are cured. Thanks to research and better treatment, survival has increased over the past 20 years. Overall, 78% of children and young people diagnosed in 1997 to 2001 survived for at least five years. This went up to 86% for those diagnosed in 2012 to 2016: a statistically significant increase. There was a marked increase in survival between these periods for children and young people with leukaemia, lymphomas, brain and spinal cord tumours, bone tumours, soft tissue sarcomas, neuroblastoma and malignant melanomas[3].

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[3] Children, teenagers and young adults UK cancer statistics report 2021

1.2 Aims and Objectives

The aim of this service specification is to define the requirements and standard of care essential for delivering services for children (up to their 16th birthday) with cancer.

The objectives of this service specification are to:

- detail the specifications required to deliver services for children with cancer for people who are resident in Wales
- ensure minimum standards of care are set for services for children with cancer
- ensure equitable access to services for children with cancer
- identify centres that are able to provide services for children with cancer for Welsh patients
- improve outcomes for people accessing services for children with cancer.

1.3 National Publications

The National Institute for Health and Clinical Excellence (NICE) published Improving outcomes in children and young people with cancer in 2005. In March 2011, the Welsh Government published the National Standards for Children with Cancer aged 0-15 years. These standards were developed to provide a foundation for the NHS in Wales to plan and deliver effective high-quality services for children under the age of 16 and are based on the NICE guidance. NWJCC published a service specification for Services for Children with Cancer in 2015 based on the National Standards.

In March 2021, the Welsh Government published The Quality Statement for Cancer which describes what good quality cancer services should look like. This focuses on nationally optimised pathways (NOPs) to support local improvement in the quality of service delivery. The NOP for children's cancer, which applies to children under the age of 16 was published in March 2022 and includes pathways for Children's Brain and Spinal Cancer, Children's Bone and Solid Tumours and Children's Leukaemia.

1.4 Relationship with other documents

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

- **NHS Wales**
    - All Wales Policy: Making Decisions in Individual Patient Funding requests (IPFR).
    - NHS Wales Health Collaborative Welsh Cancer Network: National Optimal Pathways For Children's Cancers

- **NHS Wales Joint Commissioning Committee policies and service specifications**
    - (Proton Beam Therapy Service Specification CP146

  - Proton Beam Therapy Commissioning Policy for Children, Teenagers and Young Adults (TYA) CP148
  - Specialist Fertility Services CP38
  - Blood and Marrow Transplantation Specialised Services Specification, CP79
  - Chimeric Antigen Receptor T Cell (CAR T) Therapy Policy Position PP185
  - Genomic Testing Policy Position PP184
  - Genomics Service Specification CP99
  - Sarcoma Service Specification CP149
  - Clinical Trials Policy, CP164
  - New Treatment Fund Policy, CP159

- **National Institute of Health and Care Excellence (NICE) guidance**
  - Improving Outcomes in Children and young People with Cancer CSG7 2005.
  - Improving outcomes for people with sarcoma CSG9 2006
  - Cancer services for children and young people QS55 2014
  - Haematological cancers: improving outcomes NG47 2016
  - Transition from children's to adults' services for young people using health of social care services NG43 2016
  - Fertility problems: assessment and treatment Clinical guideline CG156 2012
  - Neutropenic sepsis: prevention and management of neutropenic sepsis in cancer patients CG 151 2012

- **NHS England policies**
  - Children's cancer services: Principal treatment centres service specification 2021
  - Children's cancer services: Paediatric oncology shared care unit service specification 2021
  - Children's Cancer Services: A review on behalf of NHS England 2019/20

- **Other published documents**
  - Welsh Government: National Standards for Children with Cancer aged 0-15 2011
  - Welsh Government: The Quality Statement for Cancer 2021
  - Welsh Government: The Transition and Handover Guidance 2022
  - Royal College of Nursing: Nursing Workforce Standards 2021
  - https://siop-online.org/baseline-nursing-standards/ (The Baseline Nursing Standards for Paediatric Oncology in LMIC)

2. Service Delivery

The NHS Wales Joint Commissioning Committee will commission the services from Principal Treatment Centres for children (up to their 16th birthday) with cancer in line with the criteria identified in this specification.

Children's cancer services in Wales are organised regionally and are based on a Principal Treatment Centre (PTC) and associated Paediatric Oncology Shared Care Units (POSCUs) in accordance with the NICE Improving Outcomes Guidance. NWJCC holds the commissioning responsibility for PTCs but not for POSCUs which are the commissioning responsibility of NHS Wales local Health Boards.

2.1 Access Criteria

The service will accept referrals from primary, secondary and specialist care for children who:

- are 0 to 15 years (up to 16th birthday) **and**
- have a suspected cancer, **or**
- initial tests have determined a cancer may be or is present.

2.2 Service description

Specialised care is centralised in 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 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.

2.2.3 Principal Treatment Centres (PTCs)

The Principal Treatment Centre (PTC) provides expertise and experience in the management of an individual patient's particular type of cancer, which includes the provision of multidisciplinary care, the coordination of an individual's care with other appropriate locations and access to clinical trials and research. Such centres will have defined clinical governance structures and clear policies for transition to age-appropriate environments and specialist teams. The principal treatment centre should have the capacity to accept referrals and admit patients in a timely fashion.

The service encompasses the diagnosis, management and follow-up of children with cancer and is based on the principle that care must be age appropriate, safe, effective and delivered as locally as possible. Each child with suspected cancer should be referred to the PTC, which must make the diagnosis and direct the provision of treatment. The PTC will work in partnership with POSCUs, local specialist cancer services and supra-regional services to ensure that children receive the right care at the right time and in the right place. Access to specialist AHPs including dietitians should be available in PTC's (in line with the National Optimum Pathway). Holistic / psychosocial needs should be supported, working with psychological support services to ensure the provision of high quality care which caters to the needs of patients.

The PTC is responsible for ensuring the provision of high-quality care through the effective coordination of integrated, disease specific pathways across different providers.

PTC's should consult with patients and families on where treatment is provided.

2.3 Referral

The PTC must:

- have an agreed local process developed jointly with referring hospitals/DGHs and PTC and clear written pathways for referral to the PTC including urgent and out of hours' referrals; **and**
- respond to referrals on the day received and initiate the admission or any other clinical actions required in line with the protocols and National Optimal Cancer Pathway for that cancer type.

If the PTC does not have sufficient capacity to accept the patient, it must:

- liaise directly with other centres (ideally the closest alternative PTC) to arrange an alternative admission, **or**
- actively support the referring hospital with patient management until transfer is completed (if appropriate).

2.4 Diagnosis, Treatment and Management of Cancer

The PTC must diagnose and direct the provision of cancer care for each child diagnosed with cancer across the region. This means that the PTC must ensure that there is access to diagnostic and therapeutic expertise that is most appropriate to each child's tumour. This includes ensuring timely access to consultations with tumour or site-specific experts. The PTC should have timely access to Specialist AHPs to ensure awareness of these coming through in order to optimise patients as able prior to the commencement of treatment. A universal offer of therapies should occur to empower patients and their families and to encourage health optimisation.

Patients should also be provided with access to clinical trials where available.

2.5 Diagnosis and Decision-making - Core Service Requirements

The PTC must:

- hold weekly diagnostic and treatment multi-disciplinary team meetings (MDTs) for non-haematological malignancies. The structure of the MDTs may vary within the PTC dependent on the size and expertise of the PTC but must encompass the core and extended membership as described in 2.11 below
- hold at least fortnightly MDT meetings for leukaemia
- participate in national (UK) leukaemia MDT meetings
- hold a fortnightly psychosocial MDT and ensure that there is a holistic approach to the delivery of care. The psychosocial MDT may be either held as a standalone MDT or be incorporated alongside the children's cancer MDT or site-specific MDTs
- hold a Late Effects MDT for all children with cancer treated within the region. The Late Effects MDT must have a single named lead clinician with an agreed list of responsibilities. Core membership and extended membership must be provided in line with section 2.11 below
- for central nervous system tumours, ensure that the operational relationship between neurological, radiotherapy, neuroscience and rehabilitation services and their MDTs is defined and agreed
- ensure access to appropriate imaging and image-guided biopsy modalities, as agreed by Children's Cancer and Leukaemia Group (CCLG) guidelines
- ensure access to pathology services as per local guidelines. This must include access to acute diagnostics services and clinical pathology opinion 7 days a week
- develop pathways for genomic testing in partnership with the All Wales Medical Genomics Service (WMGS) and pathology departments to ensure access to WMGS for all eligible patients
- develop and agree treatment plans according to the following, as appropriate:
    - appropriate current UK Clinical Research Network (UKCRN) Portfolio protocol
    - Children's Cancer and Leukaemia Group (CCLG) guideline
    - other guidelines as determined by individual cancer type (e.g., sarcoma), or
    - in the case of a teenager, consider evidence for efficacy and toxicity of paediatric or adult protocols/guidelines. In exceptional circumstances, children may be treated in line with a locally approved off protocol therapy, **and**
- Communicate care plans with their relevant POSCUs using a secure electronic system.

Given the trend towards increasingly specialist interventions delivered by supra-regional specialised services, the scope of service provision delivered by each PTC may change over time. These changes may necessitate increased supra-regional working and the establishment of national clinical advisory panels, to ensure equity of access to these new therapies. The PTC will be expected to participate in these panels, as required, and adhere to any stipulated treatment protocols and pathways.

2.6 Treatment - Core Service Requirements

The PTC will provide most of the treatment for child with cancer. However, it may not provide every treatment component and must therefore comply with agreed operational and referral arrangements for such services. Such services include:

(i) Supra-Network services, and
(ii) local specialist cancer services.

Any service delivering autologous transplants must achieve accreditation by the Joint Accreditation Committee of the International Society for Cellular Therapy (ISCT) and the EBMT (JACIE), in line with relevant NHS England service specifications, within 18 months of the adoption of this Service Specification. Sites delivering HSCT services must be clearly documented in the PTC's operational policy.

The PTC must only undertake treatment for infants aged less than 1-year-old if it has specific experience and expertise in the management of cancers in this age group. Where this is not the case, there must be referral pathways and access arrangements with another PTC to ensure appropriate care for this age group where required.

The treatments provided by the PTC may be delivered entirely within the PTC or in partnership, but under the direction of the PTC, with a Paediatric Oncology Shared Care Unit (POSCU) that is located closer to home. The scope of practice and service requirements for POSCUs are set out below. The POSCU should have timely access to dietitians supporting those requesting care closer to home and link in with the specialist dietitians at the PTC for ongoing education and support.

Irrespective of where treatment is to be delivered, the PTC must:

- offer fertility preserving measures to patients and their families preparing to have treatment for cancer that is likely to result in fertility problems, taking into account the patient's diagnosis, treatment plan, urgency of treatment initiation, prognosis and likelihood of success of possible fertility preservation methods. The PTC must have a policy defining male and female fertility preservation options available and this must be supported by Network protocols and guidelines
- ensure that all cancer patients should receive contraception advice prior to treatment if appropriate, depending on age, **and**
- provide access to psychosocial support.

2.6.1 Systemic Anti-Cancer Therapy (SACT)

Systemic anti-cancer therapy (SACT) plays an important role in the treatment of children's cancers. It includes conventional chemotherapy, monoclonal antibodies/targeted therapies, intravenous, subcutaneous, intrathecal, intraventricular, and oral chemotherapy. All SACT delivered to children should be initiated by the PTC and agreed by one of the PTC MDTs. The PTC should fulfil the requirements set out in Annex i.

SACT preparation, in particular chemotherapy, may receive pharmacy support from a pharmacy which has been reviewed as part of the peer review of adult cancer services. If, at such a previous review, there was compliance with the measures regarding preparation facilities and the Control of Substance Hazardous to Health (COSHH) they will be regarded as compliant for the review of children's cancer services provided it is within the timeframes stated in those measures. The remaining preparation measures, as outlined in this Specification, should be applied specifically and separately with regards to the children's service. The responsibility for review purposes for these measures lies with the lead pharmacist.

Where SACT is administered in community settings:

- It must be administered by either nurses who have received training and competence to at least the low risk level or parents/guardians/carers trained to deliver specific SACT
- It must be prescribed, clinically checked and prepared in the PTC or a POSCU
- Where agreed and documented on the PTC SACT regimens list, some regimens may be started in hospital and continued in the community. Governance must be in place to ensure safe transport and storage of SACT in the community
- Community providers must adhere to all relevant clinical pathways and policies
- There must be clear and formal accountability processes and structures in place to ensure continuity of clinical care that is safe and effective
- There must be clear mechanisms for ensuring treatment information on the patient and SACT administration is captured and provided back to the accountable Health Board, and that all work processes are protocol led and clearly defined, **and**
- Any deviation from these protocols must be clearly documented and investigated with regular reviews, and where appropriate updated.

2.7 Clinical Trials – Core Service Requirements

Participation in clinical trials is an important component of treatment; currently around two-thirds of children are eligible for clinical trials. The PTC must ensure that each child is offered an opportunity to participate in a clinical trial, where a clinical trial for their particular cancer is available (locally or elsewhere in the UK) and it is clinically appropriate to do so. Clinical trials can be either early phase (I, II) or late phase (III or IV). Early phase trials typically involve new therapeutic agents and are only provided by centres that are accredited by the Experimental Cancer Medicines Centre (ECMC). Access to phase III clinical trials for first line therapy should be available across all PTC sites (either through local recruitment or via referral to a recruiting site). If a specific innovative therapy clinical trial is not available via the PTC in Wales, Welsh patients can be referred to sites outside Wales. Where studies are not commercially funded, there may be excess treatment costs (ETCs) involved. An application to Health and Care Research Wales must be made to cover the ETCs during the trial set up or before a Welsh patient is referred for the trial elsewhere. Please see Health and Care Research Wales ETCs guidance, and NWJCC Clinical Trials policy for further information.

In addition, where possible, each child (or, where relevant, the persons with parental responsibility over the child) should be given the opportunity to have their (or their child's) clinical details and pathology samples included in a relevant biobank subject to consent, in line with protocol and biobank regulations.

2.8 Palliative Care - Core Service Requirements

When the aim of treatment is not curative, the PTC will provide palliative and end of life care and bereavement support. The PTC will also support the co-ordination of care outside specialist centres through shared care services and in liaison with local community and palliative care services. Specialist cancer palliative care advice and treatment is directed by specialist palliative care teams with some palliative care services delivered within POSCUs or at home. Specialist teams provide expert advice on all aspects of symptom control and psychological support for the child and their family and will be part of a wider paediatric palliative care network. It is recognised that these teams will be working with other non-cancer agencies to deliver palliative support e.g. Children's Hospices and Children's Community Nursing Teams, and other community-based services to provide end of life care and bereavement support.

AHPs are an integral member of the MDT. There should be appropriate referral processes in place to ensure patients and their families can access the appropriate therapist when required.

Many children and their families have a preference for end of life care to be delivered at home. End of life care must include access to 24-hour palliative care support, provided in partnership with paediatric palliative care services in order to deliver 24/7 care to the child and family at home. End of life pathways must be approved by the Network.

2.9 Survivorship, Long Term Follow-Up and Late Effects Service

Aftercare pathways commence on completion of treatment. At a point along the aftercare pathway, one which will vary between PTCs, a patient's care will be transferred from the disease specific multi-disciplinary team (MDT) to the Late Effects MDT. In order to facilitate communication and co-ordination of care and ensure rapid re-access into the service, a single point of access must be made available to patients within the Aftercare pathway.

On completion of treatment, the PTC must ensure there is a comprehensive long term follow up package in place for every child or teenage cancer survivor which addresses the following:

- **Clinical risk stratification and follow-up model**: each patient must be allocated a risk level using a clinical risk stratification tool, such as that developed by the National Cancer Survivorship Initiative (NCSI). The risk level must be appropriate for the individual, taking into account psychosocial factors as well as diagnostic and treatment factors and must be documented within the care plan. The NCSI tool allocates patients into one of three levels, supported self-management, a shared care system or hospital-based follow- up for the most complex care needs.
- **End of treatment summary**: this must be prepared for every patient within a prescribed period of them transferring to a late effects follow-up service. All patients will continue to receive routine follow-up until transfer is clinically appropriate. The patient /family and GP will be provided with a summary.
- **Individualised care plan**: this must be reviewed and modified at intervals throughout follow-up and must include:
    - type and planned frequency for surveillance of the original cancer
    - potential late effects and recommended surveillance based on national or international standards
    - health education, which should be delivered by a range of professionals including AHP's who can make a significant contribution to long term health and wellbeing and be integrated in any long-term follow up/late effects service; in addition, consider any education requirements to support local services if specialist knowledge is required to support children and teenage cancer survivors
    - psychological assessment and support. Psychological support services should be offered to patients within their local area / outside of the PTC where appropriate, with access and referral supported by the PTC
    - The care plan must be shared with the patient and/or parent at the end of the treatment and copied to the GP and all involved professionals
    - An end of treatment summary must be made available as soon as possible once treatment is finished.

2.10 Facilities and equipment

Treatment for children with cancer is complex and intensive, and children can often become acutely ill during treatment, requiring a high level of medical support. As a result, care for children with cancer is mainly provided on an inpatient basis. The service must be delivered in an age appropriate setting, which means that the PTC must:

- Ensure there are dedicated facilities for children with cancer including:

  - Named wards for inpatient chemotherapy. These must be documented in a written policy and patients must be admitted to these wards in preference to other wards
  - An agreed number of single rooms (not one room only) for inpatient isolation, each with an en-suite toilet and washing facilities
  - Separate day care facilities for children with waiting and play areas
  - Access to dedicated day care recovery beds (i.e., a ward or room(s)). These must be documented in a written policy and on the days that the PTC's day care facility is being used, the rooms must only be used for patients who are resting after day care treatments or after invasive investigation, or for other outpatients who have had clean day care procedures
  - Paediatric resuscitation equipment must be in all rooms where day care treatment takes place and this equipment should be checked at least weekly or line with the PTC's protocols
  - Regular children's outpatient clinics which are exclusive to patients under the care of PTC and are identified as a contact point for referral in the primary care referral guidelines
  - Facilities for parents including, but not limited to, an overnight bed alongside the patient, **and**
  - A dedicated, multi-disciplinary rehabilitation space on the ward should be available to provide education and support to the patient and their families, e.g. to optimise nutritional status.

- The pathology services supporting the PTC must:
  - Comply with Clinical Pathology Accreditation (UK) Ltd (CPA) and the Human Tissue Authority (HTA)
  - Comply with Royal College Minimum Dataset
  - Provide acute diagnostics services and clinical pathology opinion 24/7
  - Have access to digital pathology and networked services, including remote working
  - Have in place blood management guidelines
  - Participate in and encourage clinical trial activity, **and**
  - Provide a framework for staff education.

2.11 Staffing

Principal treatment centres need 24-hour access to specialist medical, nursing and therapy staff with the required skills and expertise to support patients with a wide range of cancers and associated complications. Specialisation in paediatric cancers is generally not site-specific as it is in adults because of the relatively small number of patients, but specialisation does occur for CNS tumours, haematological malignancies and solid tumours; adequate cross-cover arrangements are required.

Each PTC must:

- Ensure there is a consultant medical on-call rota in place which fulfils the following requirements:
    - Consultant cover is provided 24/7
    - The on-call rota is staffed wholly by named consultants, each of whom is a paediatric oncologist or haematologist employed at the PTC and providing inpatient care as part of their timetable during normal working hours
    - The on-call individual is available to give advice to enquiring clinicians regarding paediatric cancer patients being managed anywhere in the region, whether in hospital or in the community
    - The on-call individual is available to attend hospitals facilities of the PTC when required.
- Ensure there is resident cover rota for the PTC whereby there is 24/7 resident on-call cover from medical staff in paediatrics of Specialty Training (ST) 3 minimum level of seniority
- Ensure that treating clinicians are members of the Children's Cancer and Leukaemia Group (CCLG), with all staff within the service encouraged to be members also
- Ensure that there is a professional head of the SACT service that is directly responsible for the development, management and ultimate clinical accountability and responsibility for the service. This professional head of service must hold an appropriate qualification to practice and be registered with the GMC or Health Professions Council
- Ensure that there is a Lead Nurse for the service
- Ensure that there is tumour based clinical nurse specialists (CNS's) and paediatric oncology outreach nurses (POONs) available for all patients
- Ensure that nurses who administer chemotherapy to children have been assessed as competent to do so, in line with the relevant quality measures
- Maintain a register of all staff that have completed chemotherapy competency-based training
- Ensure there is a named Nurse Trainer for the service, with responsibility for training in chemotherapy administration
- Ensure support from a pharmacy team specialising in children's cancer. This must include:
    - A lead pharmacist (team manager) and number of designated pharmacists for the children's cancer service. Sufficient staffing should be in place to ensure that there is a safe and effective service, and
    - A single named designated pharmacist for the aseptic chemotherapy preparation facilities of the pharmacy service.
- Any staff responsible for reconstituting SACT must have undergone training in line with:

  - Health and Safety Commission approved Code of Practice, The Control of Substance Hazardous to Health (COSHH, 2008)
  - Assurance of aseptic preparation of medicines in NHS Wales Welsh Government February 2024
  - Rules and Guidance for Pharmaceutical Manufacturers and Distributors (the 'Orange Guide') (MRHA, 2017); and
  - Quality Assurance of Aseptic Preparation Services 5th Edition (Beaney, AM. 2017).
- Children's cancer services must take a multi-agency approach to support and address the wider social, educational, psychological and emotional needs of the child and family. As a result, all PTCs must ensure that:
- There is ready access to neuropsychology for the assessment and input for children with disease acquired or treatment related brain injury and specialist psychology, and liaison psychiatric services to address more complex psychological morbidity associated with cancer treatment
- There is access to a wider range of services/professionals including:
  - Health play specialists
  - Social workers
  - Educational support including teachers
  - AHP's including Dietetics
  - Physiotherapy
  - Occupational Therapy
  - Speech and Language
  - Rehabilitative support.

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

- Nurse training including training in chemotherapy skills and management of its consequences. It is recognised in national guidance that the nursing contribution in cancer teams is critical to the success of these services
- Post registration nursing staff will need to develop specialist skills through a combination of in-house development programmes, degree pathways or other relevant postgraduate modules
- Specialist nurses are needed to support the service in identified roles such as Advanced Nurse Practitioner, and in areas such as long-term follow-up, clinical trials, bone marrow transplant, intravenous therapy, cryopreservation, stem-cell transplants and education and nursing research. The nursing teams also need to work effectively outside of hospitals by providing outreach, and support to local POSCU and community teams
- Medical training in line with above where applicable for chemotherapy
- Specialist pharmacy training in order to enable:

  - (i) chemotherapy prescription verification
  - (ii) clinical screening of supportive care prescriptions
  - (iii) safe implementation of clinical trials and new drugs
  - (iv) safe implementation of electronic prescribing of SACT.
- Access to specialist resource materials
- "Good Clinical Practice" in Clinical Trials training.

Time must be allocated for mandatory training and to maintain and develop cancer skills for all staff disciplines.

2.11.1 Specialist teams

The **core team** common to all PTC MDTs must include the following staff with expert skills in oncology:

- Specialist nurse
- Cancer pharmacist, from the designated pharmacists of the cancer pharmacy service supporting the PTC's chemotherapy service. Pharmacy input is required for all chemotherapy treatment decisions; however, membership can be through direct attendance at the MDTs or through access to the MDT outcomes and direct attendance at other multidisciplinary team meetings where SACT treatment planning is undertaken
- MDT co-ordinator and secretary
- Specialist AHP teams
- Play specialists.

2.11.2 Extended membership of all PTC MDTs must include:

- Representation from the in-patient and out-patient paediatric cancer nursing team

In addition, the following must be included. Please note each named clinician must have a deputy who will cross cover when they are absent.

For a PTC with a single MDT:

- paediatric oncologists with responsibility for solid tumours
- paediatric haematologists with responsibility for haematological malignancy
- clinical oncologists with responsibility for paediatric radiotherapy
- radiologist
- histopathologist
- cytogeneticist
- paediatric surgeon
- neurosurgeon

- neuropathologist
- neuroradiologist
- neurology specialist.

For a PTC with a separate haematological malignancy MDT:

- paediatric haematologists with responsibility for haematological malignancy
- histopathologist
- cytogeneticist

Extended membership for a haematological malignancy MDT must include:

- Clinical oncologists with a responsibility for paediatric radiotherapy

For a PTC with a separate non-CNS solid tumour MDT:

- paediatric oncologists with responsibility for solid tumours
- clinical oncologists with responsibility for paediatric radiotherapy
- radiologist
- histopathologist
- paediatric surgeon

For a PTC with a separate children’s CNS tumour MDT:

- paediatric oncologists with responsibility for CNS malignancy
- clinical oncologists with responsibility for paediatric CNS radiotherapy
- neurosurgeon
- neuropathologist
- neuroradiologist
- neurologist.

An NHS employed member of the core or extended team should be nominated as having specific responsibility for users' and carers' issues and information.

A member of the core team should be nominated as the person responsible for ensuring that recruitment into clinical trials and other well-designed studies is integrated into the function of the MDT.

Late Effects MDT at the PTC:

The Late Effects MDT must have a single named lead clinician with an agreed list of responsibilities. Core membership must include:

- Clinical Nurse Specialist
- Endocrinologist
- Paediatric or TYA oncologist/haematologist
- Psychologist
- Clinical care co-ordinator
- MDT co-ordinator
- Allied Health Professionals

Extended membership of the Late Effects MDT may include representatives from additional clinical services and allied health professionals who may have a role in the management of patients within the Aftercare pathway. These members may include:

- Clinical oncologist
- Social worker
- Allied health professionals
- Fertility specialist
- Cardiologist
- Nephrologist
- Gynaecologist
- Representative from memory service
- Gastroenterologist

The extended membership list is not exhaustive, and membership of the Late Effects MDT may be extended.

2.12 Interdependencies with other services or providers

PTCs have a range of critical co-dependencies with other clinical services. The following clinical services must be delivered on-site at every PTC:

- Paediatric oncology services
- Paediatric cancer pharmacy services
- Paediatric haematology services
- Paediatric radiology services
- Paediatric critical care (Level 3)
- Paediatric surgery, to include management of emergencies, central lines and biopsy services (where these are not provided by interventional radiology or anaesthetics)

- Paediatric anaesthetics and pain management
- Therapy services (such as psychology, physiotherapy, Dietetics, Speech and Language Therapy , Occupational therapy)
- Play specialists.

The following clinical services do not necessarily need to be delivered on-site, but PTCs need to ensure the services are readily available to access (if not delivered on-site):

- Radiotherapy services
- Endocrinology services
- Neurosurgery (for centres treating children with neuro-oncological diseases)
- Nephrology services
- Ophthalmology service
- Gastroenterology service
- Cardiology services
- Paediatric oncology surgery (other than management of emergencies, central lines and biopsy services)
- Paediatric pathology
- Genomic testing
- Paediatric Infectious Disease
- Palliative care
- Other specialist paediatric surgery

PTCs should ensure there are clear referral and management pathways in place for the following services (if not delivered on-site):

- HSCT (both autologous and allogeneic)
- Liver cancer surgery
- Sarcoma and services including bone cancer surgery
- Other specialist surgery
- Retinoblastoma and
- Proton Beam Therapy.

Other related co-dependent services include:

- Local authority-based services for education and social services
- Child and adolescent mental health services
- Primary Care
- Community services
- Palliative care services.

2.13 Designated Primary Treatment Centres

South Wales
Children's Hospital for Wales
University Hospital of Wales
Heath Park Way
Cardiff
CF14 4XW

North Wales
Alder Hey Children's Foundation NHS Trust
Alder Hey Children's Hospital Oncology Unit
Eaton Rd
Liverpool
L12 2AP

Mid Wales
Birmingham Women's and Children's Hospital NHS Foundation Trust
Oncology Unit
Birmingham Children's Hospital
Steel house Lane
Birmingham
B4 6NH

2.14 Clinical Standards

PTCs should ensure that the SACT service is delivered safely and that it conforms to appropriate standards, guidance and best practice, in particular those set out in:

- Manual for Cancer Services: Children's Cancer Measures (National Cancer Action Team, 2013)
- Improving Outcomes in Children and Young People with Cancer (NICE, 2005)
- National standards set following National Patient Safety Agency (NPSA) oral and vinca-alkaloid alerts (2008)
- Systemic Anti-Cancer Therapy: For Better or Worse (National Confidential Enquiry into Patient Outcomes and Death (NCEPOD), 2008)
- Chemotherapy Services in England: Ensuring quality and safety (National Chemotherapy Advisory Group (NCAG), 2009)
- Guidance on the administration of intrathecal chemotherapy (Department of Health, 2008)
- On the Right Course: A review of the quality of care provided to patients receiving systemic anti-cancer therapy. (National Confidential Enquiry into Patient Outcome and Death (NCEPOD), 2018)

2.15 Paediatric Oncology Shared Care Units

Shared care enables children with cancer to receive supportive care and, where agreed, specified chemotherapy treatment(s) as close to home as possible and importantly, facilitates appropriate access to local community support services.

Local services should be planned and managed to consider capacity, training and development needs, in order to ensure appropriate access to all relevant professionals including AHP's to ensure equity of care from tertiary to secondary care centres for those requiring treatment closer to home within the POSCU.

2.16 Transition to TYA and Adult Services

Transitional care is essential to ensure seamless provision of care from paediatric to TYA and then onto adult cancer/late effects services and should be defined for each tumour specific pathway within the region. The PTC must ensure that transition to TYA or adult services is:

- pre-planned and pro-active so that patients know what to expect and when transition is required
- occurs at a time of stability in the patient's disease and treatment and may be effectively achieved during therapy and after completion of treatment
- involves close liaison between the referring and receiving teams to ensure that the transition process is seen as a positive step and to minimise anxiety that patients and families may feel (e.g. by having joint transition arrangements)
- is in line with NICE[4] and Welsh Government[5] guidance.

2.17 Acceptance Criteria

The service outlined in this specification is for patients ordinarily resident in Wales, or otherwise the commissioning responsibility of the NHS in Wales. This excludes patients who whilst resident in Wales, are registered with a GP practice in England, but includes patients' resident in England who are registered with a GP Practice in Wales.

2.18 Exceptions

If the patient does not meet the criteria for treatment as outlined in this policy, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the All Wales IPFR Panel.

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[4] Transition from children's to adults' services for young people using health of social care services NG43 2016

[5] Welsh Government: The Transition and Handover Guidance 2022

If the patient wishes to be referred to a provider outside of the agreed pathway, an IPFR should be submitted.

Further information on making IPFR requests can be found at: Individual Patient Funding Requests.

3. Quality and Patient Safety

The provider must work to written quality standards and provide monitoring information to the lead commissioner. The quality management systems must be externally audited and accredited.

The centre must enable the patients, carers and advocates informed participation and to be able to demonstrate this. Provision should be made for patients with communication difficulties, for example patients with learning difficulties and those who may be more comfortable communicating in Welsh, and for children, teenagers and young adults.

3.1 Quality Indicators (Standards)

No.	Indicator
PTC Clinical Outcomes	
101	Proportion of patients with a solid tumour with a recorded stage of 1 or 2 at diagnosis.
102	Proportion of patients with metastatic disease at diagnosis.
103	Median time from onset of symptoms to diagnosis.
104	Proportion of patients with leukaemia who progress or relapse.
105	Proportion of patients with CNS tumours who progress or relapse.
106	Proportion of patients with non-CNS solid tumours who progress or relapse.
107	Number of deaths within 30 days of chemotherapy.
108	Proportion of eligible patients recruited to a nationally available trial.
109	Proportion of patients completing treatment, who receive an end of treatment summary within 6 months of the end of treatment.
110	Proportion of patients offered the opportunity to tumour bank
111	Proportion of patients who have had tumour samples banked.
112	Proportion of patients admitted into ICU within 30 days of the end of a chemotherapy cycle.
113	1 year survival
114	5 year survival
115	Time from onset of fever to administration of antibiotics in neutropenic fever.
Patient Outcomes	
201	There is information for patients and families as set out in the service specification.
202	There is a 24/7 advice service for patients and carers
203	There is a mechanism in place to obtain feedback from patients and families.
Structure & Process	
001	There is an Operational Delivery Network in place for children’s cancer services.
002	There is specialist paediatric oncology staffing across all PTC sites in the Network.
003	There is a SACT head of service and a lead and designated pharmacists
004	There is a 24/7 consultant on call rota and resident on call rota
005	There are MDT meetings for diagnosis, treatment and psychosocial management
006	There are late effects MDT meetings
007	There is a network agreed competency based training programme for oncology and SACT
008	There are specified wards for administration of SACT
009	There are network agreed clinical guidelines including SACT regimens and protocols in place

010	There are policies in place for the safe administration of SACT
011	There are network agreed patient pathways in place.
012	There is a policy in place for transition
013	The PTC is submitting all relevant information to the national databases
014	Clinical trial eligibility is discussed with every patient and family where an appropriate trial is available either at the PTC or at another PTC.

3.2 Patient Information and Consent

Patient and Carer Information must be provided which covers generic and tumour specific information for children with cancer.

Each provider and health care practitioner must comply with the relevant legislative framework and relevant guidance governing consent. Accordingly, each provider and health care practitioner must ensure that all children and young people who use services are:

- fully informed about their care, treatment and support and information must be age-appropriate;
- able to take part in decision making to the fullest extent possible; and
- asked if they agree for their parents or guardians to be involved in decisions they need to make.

(Guidance for providers on meeting the regulations, Care Quality Commission, 2015).

Further guidance on children's consent can be found through the General Medicine Council.

It is important that patients, parents and carers receive clear written guidance when consenting to treatment, this must include the following:

- Treatment intent
- Prognosis and potential complications associated with their treatment
- Clear instructions who to contact if they need advice outside working hours including phone numbers for 24/7 advice lines (either at the PTC or POSCU)
- How to proceed in the event of a medical emergency, in particular following SACT
- Information on how to manage and care for a central line (where appropriate).

3.3 Other quality requirements

- the provider will have a recognised system to demonstrate service quality and standards
- the service will have detailed clinical protocols setting out nationally (and local where appropriate) recognised good practice for each treatment site

- the quality system and its treatment protocols will be subject to regular clinical and management audit
- the provider is required to undertake regular patient surveys and develop and implement an action plan based on findings. Feedback and involvement from a diverse range of patients is encouraged.

4. Performance monitoring and Information Requirement

4.1 Performance Monitoring

NWJCC will be responsible for commissioning services in line with this policy. 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
- Service providers to evidence compliance with standards of care

NWJCC will conduct performance and quality reviews on an annual basis

4.2 Key Performance Indicators

The providers will be expected to monitor against the full list of Quality Indicators derived from the service description components described in Section 3.1.

4.3 Date of Review

This document is scheduled for review before December 2027 where we will check if any new evidence is available.

If an update is carried out the policy will remain extant until the revised policy is published.

5. 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 NHS Wales Joint Commissioning 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.

6. Putting Things Right

6.1 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 must 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.

If 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 NWJCC.

6.2 Individual Patient Funding Request (IPFR)

If the patient does not meet the criteria for treatment as outlined in this policy, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the All Wales IPFR Panel.

If an IPFR is declined by the Panel, a patient and/or their NHS clinician has the right to request information about how the decision was reached. If the patient and their NHS clinician feel the process has not been followed in accordance with this policy, arrangements can be made for an independent review of the process to be undertaken by the patient's Local Health Board. The ground for the review, which are detailed in the All Wales Policy: Making Decisions on Individual Patient Funding Requests (IPFR), must be clearly stated.

If the patient wishes to be referred to a provider outside of the agreed pathway, and IPFR should be submitted.

Further information on making IPFR requests can be found at: Individual Patient Funding Requests

Annex i Systemic Anti Cancer Treatment (SACT)

Centres providing SACT should:	**Enhanced POCSU**		**PTC**
	Level A	**Level B**	
Ensure that there are arrangements in place to support urgent SACT treatment prior to MDT discussion			Y
Agree an approved list of SACT treatment regimens which is updated annually – this should reflect regimens and elements of regimens that are suitable to administer in community settings, i.e., low risk only			Y
Ensure that treatment is given in accordance with agreed Network treatment protocols	Y	Y	Y
Assess and secure Network agreement for all new treatments prior to their introduction to ensure that they fit with strategic plans			Y
Agree a policy defining the steps required for use of regimens not on the approved protocol list. Deviations should be recorded and audited on a regular basis			Y
Ensure that there is a robust system of clinical governance in place and that all staff are fully familiar with the treatments employed within the Service and have been trained and deemed competent to deliver them			Y
Ensure that chemotherapy is prescribed using an e-prescribing system (Contract particulars, Schedule 4 – National Quality Requirements). It is acknowledged that some providers may be working towards compliance with this requirement and will therefore have implementation plans in place which have been agreed with local commissioners	Y	Y	Y
Ensure that SACT is only be prescribed by staff who are authorised and registered to prescribe SACT in the PTC			Y
Ensure SACT prescriptions are checked by a children's cancer pharmacist who has undergone specialist training and is locally authorised. Where a pharmacist non -medical prescriber prescribes SACT a second children's cancer pharmacist is still required to verify the prescription			Y

Centres providing SACT should:	**Enhanced POCSU**		**PTC**
	Level A	**Level B**	
Undertake pre-chemotherapy treatment assessments for all patients to ensure: • Accurate pre-SACT assessment to enable variation from the patient's baseline to be detected; • Pre-course and pre-cycle records meet all requirements of the relevant SACT; and • That the patient is confirmed to be fit to proceed and all pre- cycle/course investigations are within the limits defined in the protocol	Y	Y	Y
Ensure that all female patients of child bearing age have a pregnancy test prior to initiation of SACT	Y	Y	Y
Put in place local arrangements to ensure that, as far as is practicable, high cost items are only reconstituted after the patient's blood results are known. All SACT must be prepared in accordance with locally approved policies and protocols	Y	Y	Y
Put in place a local policy which sets out that SACT treatment should be commenced during standard 'working hours', wherever possible. This is to ensure that support services and expert advice is available. The policy must also state which, and only which, exceptional circumstances the initiation of administration of chemotherapy may be allowed outside "normal working hours" and the arrangements for administering SACT which then apply	Y	Y	Y
Ensure that there are on-site facilities for the management of central venous access devices with defined surgical support at the PTC and at other agreed sites, so that the administering practitioner can ensure appropriate venous access for the chemotherapy to be administered	Y	Y	Y
Ensure that the SACT service is delivered safely and that it conforms to appropriate standards, guidance and best practice, in particular those set out in 'Clinical Standards'	Y	Y	Y
Put in place a policy detailing the safe reconstitution of cytotoxic drugs. Manipulating and reconstituting cytotoxics poses the greatest risk, for this reason, cytotoxics should only be reconstituted in an accredited and regulated/audited pharmacy aseptic unit by appropriately trained and experienced staff; and	Y	Y	Y
Following treatment with SACT, the responsible clinician should confirm to both the patients GP and the referring clinician; what treatment has been delivered, the patient's condition and any post treatment arrangements; and	Y	Y	Y
Submit data to the national SACT database	Y	Y	Y

Annex ii Abbreviations and Glossary

Abbreviations

AWMSG	All Wales Medicines Strategy Group
CCLG	Children's Cancer and Leukaemia Group
CNS	Central Nervous System
CNS's	Clinical Nurse Specialists
COSHH	Control of Substance Hazardous to Health
CPA	Clinical Pathology Accreditation
EBMT	European Group of Bone Marrow Transplant
ECMC	Experimental Cancer Medicines Centre
GMC	General Medical Council
GP	General Practitioner
HTA	Human Tissue Authority
IPFR	Individual Patient Funding Request
ISCT	International Society for Cellular Therapy
JACIE	Joint Accreditation Committee
MDT	Multi-disciplinary Team
NCSI	National Cancer Survivorship Initiative
NHS	National Health Service
NWJCC	NHS Wales Joint Commissioning Committee
POONs	Paediatric Oncology Outreach Nurses
POSCU	Paediatric Oncology Shared Care Units
PTC	Principal Treatment Centre
ReDA	Clinical Trial Management System
SACT	Systemic anti-cancer therapy
SMC	Scottish Medicines Consortium
ST	Speciality Trainee
TYA	Teenagers & Young Adults

WMGS	Wales Medical Genomics Service

Glossary

Individual Patient Funding Request (IPFR)

An IPFR is a request to NHS Wales Joint Commissioning Committee (NWJCC) to fund an intervention, device or treatment for patients that fall outside the range of services and treatments routinely provided across Wales.

NHS Wales Joint Commissioning Committee (NWJCC)

NWJCC is a joint committee of the seven local health boards in Wales. The purpose of NWJCC is to ensure that the population of Wales has fair and equitable access to the full range of Tertiary Services. NWJCC ensures that services within our portfolio are commissioned from providers that have the appropriate experience and expertise. They ensure that these providers are able to provide a robust, high quality and sustainable services, which are safe for patients and are cost effective for NHS Wales.