

SCHEDULE 2 – THE SERVICES

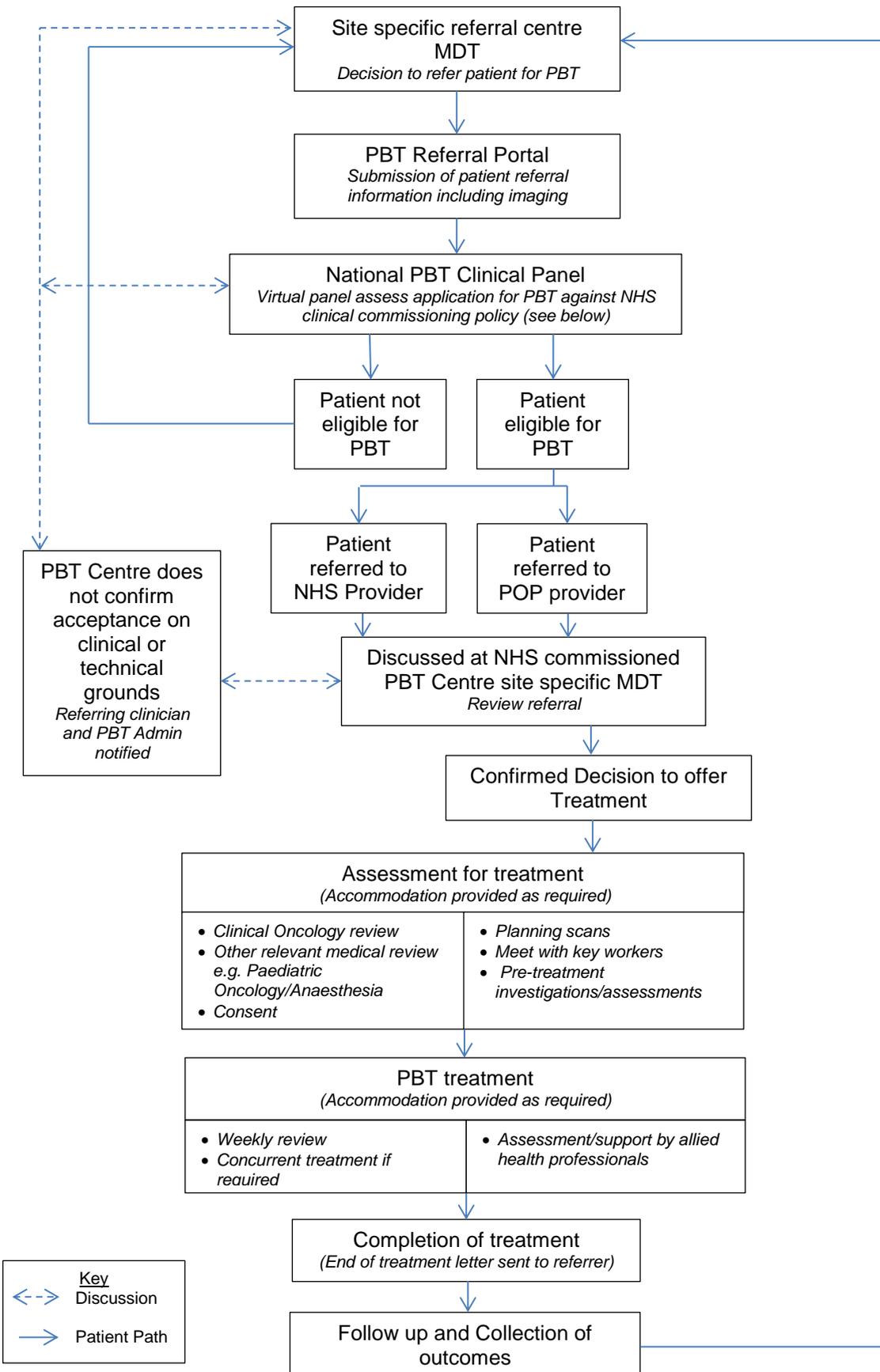
A. Service Specifications

Service Specification No:	170071S
Service	Proton Beam Therapy Service (All Ages)
Commissioner Lead	<i>For local completion</i>
Provider Lead	<i>For local completion</i>

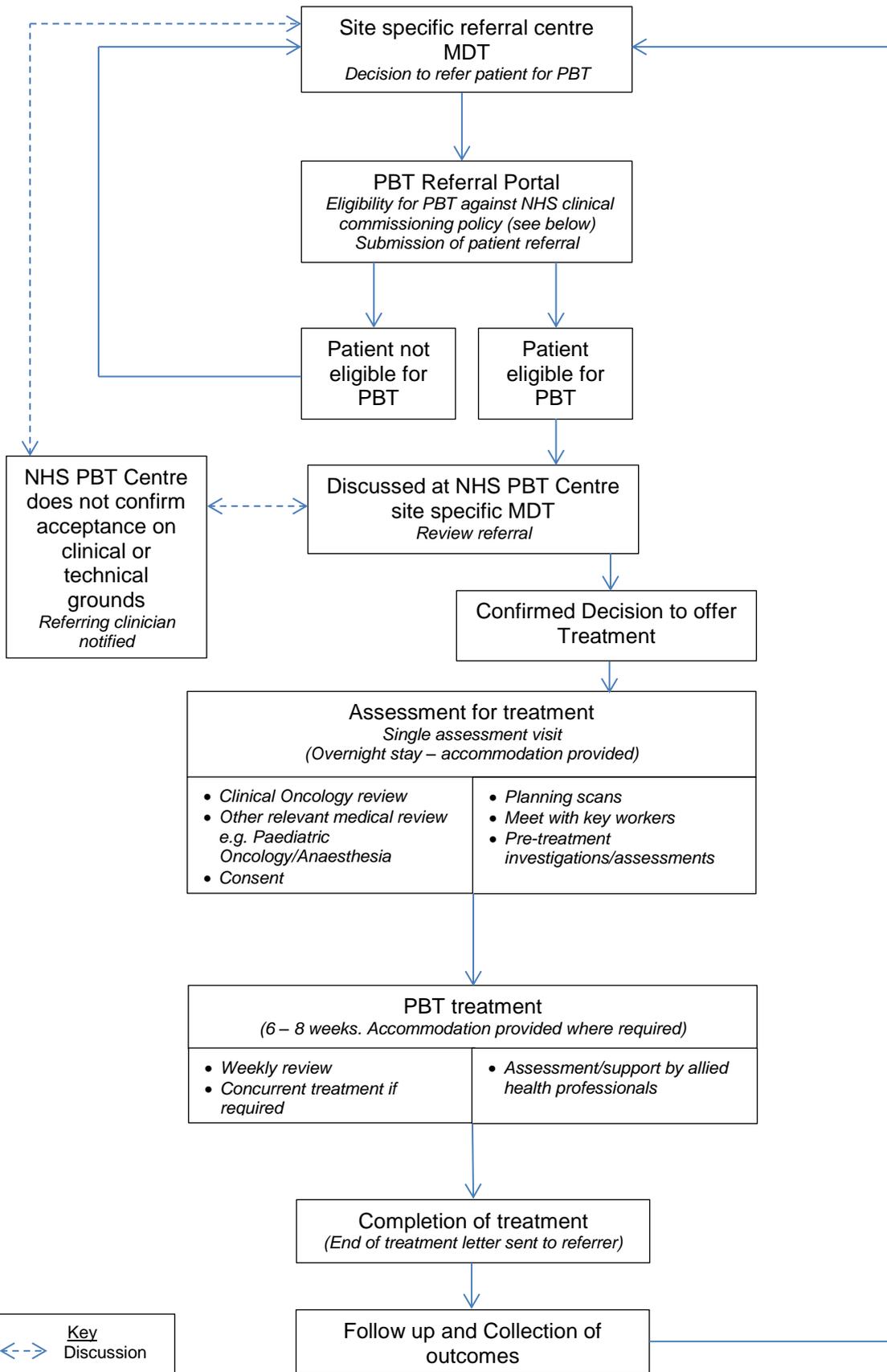
1. Scope	
1.1	<p>Prescribed Specialised Service This service specification covers the provision of Proton Beam Therapy Service (All Ages)</p>
1.2	<p>Description Proton Beam Therapy (PBT) provides radiation by delivering a beam of proton particles, rather than X-Rays. The physical properties of protons results in almost no radiation dose being deposited in the normal tissue beyond the tumour. This is in contrast to X-rays where there is dose extension beyond the tumour.</p>
1.3	<p>How the Service is Differentiated from Services Falling within the Responsibilities of Other Commissioners This service is only commissioned by NHS England. CCGs do not commission any elements of this service as the cost of providing the building and specialist equipment is extremely high and the number of expert clinical staff and technicians that can provide the service is very small.</p> <p>Activity is identified via National Radiotherapy Dataset (RTDS) data flows which apply to Highly Specialist Proton Beam Therapy Centres only</p>
1.4	<p>Background Since 2008, the NHS has referred patients eligible for PBT to service providers overseas for treatment. From Autumn 2018, the first centre for the national NHS PBT service in England will be operational, followed by a second centre in 2020. Each NHS PBT centre will take approximately 18 months to become fully operational, with some patients still needing to travel overseas for treatment during this period. Further explanation on how referral pathways will work during and after this transition period is provided below.</p> <p>Pathway 1 enables the referral of eligible patients to the NHS PBT service and NHS commissioned overseas PBT providers, until such time as the NHS PBT service is able to accommodate all demand from NHS referrers. At this point Pathway 2 will operate alone. Pathways 1 and 2 may run concurrently depending on available capacity, demand for conditions and indications during the transitional ramp up period of the NHS facilities</p>

2. Care Pathway and Clinical Dependencies

2.1 Referral and Care Pathway 1 (NHS & POP – see 2.2 below)



Referral and Care Pathway 2 (NHS only see 2.2 below)



Key
 <--> Discussion
 → Patient Path

Referral for radiotherapy treatment (including PBT) is made to a consultant clinical oncologist who is a member of tumour specific multi-disciplinary teams (MDT). Decisions on treatment and the overall treatment plan must relate back to an MDT discussion and decision.

Please note that access to treatment will be guided by applicable NHS England national clinical commissioning policies and any applicable evaluative commissioning schemes or clinical trials.

The provider may refer the patient back to the referring centre if the patient is considered not to be complying with their treatment regime. The provider must have discussed this with the patient and the referring centre, explaining the reasons for treatment withdrawal and actions the patient and/or referring centre need to take. The provider must inform NHS England when treatment is withdrawn and actions taken to prevent and mitigate this action.

2.2 Interdependence with other Services

The provision of PBT treatment must be viewed in the context of the wider range of other services which a patient may need access to, often concurrently. The PBT service must therefore be hospital based to ensure optimum integration with these services and patient sensitive treatment scheduling. The relevant services are listed below, each of which may be specified in existing NHS frameworks with appropriate capacity:

- Oncology – paediatric, teenage and young adult (TYA) and adult
- Specialist out-patient anaesthetic services
 - includes induction & recovery rooms
 - for children, delivered by a trained paediatric anaesthetist
- Endocrinology
- Specialist head & neck cancer surgery
- Sarcoma surgery
- Neurosurgery
 - Paediatric & adult neurosurgery
 - Specialist skull-based neurosurgery
 - Specialist spinal surgery
- In-patient and out-patient chemotherapy
- In-patient services, e.g. acute admission, rehabilitation
- Conventional radiotherapy including relevant (to PBT case mix) site specialist teams
- Site specialist radiology - paediatric and adult
- Play therapy – paediatric only
- Allied health and psychosocial services as required, including but not exclusive
 - Psychology
 - Occupational Therapy
 - Physiotherapy
 - Dietetics
 - Speech & Language Therapy
- Paediatric hospital services, including paediatric intensive care.
- Ensure that the paediatric service has formal specialist academic leadership and links
- Established links with (or part of) University/Academic centre
- Access to additional support services
 - Accommodation for patients and carers
 - GP services for patients and carers
 - Support services for patients and carers (e.g. social services, charities, education)

2.3 Specialist Team

The PBT service must have a specialist team of staff appropriately trained in the delivery of PBT. Every patient will have a named key worker.

The team must include:

- clinical oncologists
- therapy radiographers
- physicists
- anaesthetist
- health play specialists
- medical engineers
- dosimetrist
- administrative support
- qualified nurses
- allied healthcare professionals (as required)
 - occupational therapists
 - physiotherapists
 - psychology

Fully constituted multi-disciplinary teams must be in place that recognise/evaluate the whole patient pathway not just the delivery of protons.

2.4 Anaesthesia

Anaesthesia must be provided by an appropriately trained and experienced anaesthetist. They should have advanced training in paediatric life support and maintain these competencies by annual training that is, ideally, multi-disciplinary and scenario based. All those anaesthetising children should have at least Level 2 training in child protection and safeguarding and this must be maintained by annual updates of current policy, practice and case discussion. All the above competencies must be assessed through the annual appraisal process.

In addition to the above there must be in place:

- Lead theatre practitioner/ODP
- Pre-anaesthesia assessment
- Appropriately trained recovery staff
- Standard and established pathway for paediatric resuscitation
- Standard and established pathway for paediatric intensive care retrieval and transport for when critical care is required with an NHS provider that meets NHS England standards as set out in service specification *Level 3 Paediatric Intensive Care*.

2.5 Equipment & Facilities

The PBT centre must have a minimum of 2 proton treatment rooms which must include:

- accelerator(s) and beam line infrastructure to enable treatment within each of the treatment rooms;
- a rotating gantry remotely controllable from outside the treatment room and enable any beam angle approach angle for a supine patient;
- patient couch that allows for non-coplanar irradiation and 6 degrees of freedom;
- a scanning nozzle capable of intensity modulated proton therapy;
- patient flow should incorporate separate adult and paediatric workflow;
- the facilities and equipment should allow for the full unhindered use of general anaesthesia within the treatment room.

The following equipment is required for the delivery of proton treatment:

- integrated treatment planning service with specialist proton therapy planning software
- integrated CT /MRI pre-treatment imaging
- in treatment position volumetric imaging for patient set up and monitoring.

All equipment must comply with radiation protection, medical device, health and safety and other relevant legal requirements and standards.

The following will also be provided:

- Consulting rooms (multi-use)
- Play and reception areas
- Refreshment areas
- Accommodation for patients and carers which is suitable for a long-term stay (6-8 weeks) and should include
 - en-suite facilities
 - facilities to enable self-catering
 - laundry facilities

3. Population Covered and Population Needs

3.1 Population Covered By This Specification

- Patient eligibility for PBT is set out in the NHS England Clinical Commissioning policies
- The eligible population from a commissioner responsibility perspective are:
 - All ages
 - Falls within the direct commissioning responsibility of NHS England
 - Falls within the direct commissioning responsibility of the devolved administrations NHS Scotland, NHS Northern Ireland and other UK territories for which an agreement is in place.
- This NHS England contract includes provision for the service to treat eligible patients from overseas under S2 and aligned referral arrangements. Providers are reimbursed for appropriately referred and recorded activity as part of this contract.
- NHS Trusts performing procedures on patients outside of S2 arrangements and aligned referral arrangements will need to continue to make the financial arrangements directly with the governments involved, separately from their contract with NHS England.

3.2 Population Needs

Capacity has been commissioned for clinical indications for which there is a current evidence base and for indications for which it is expected to establish an evidence base through research and/or clinical trials.

PBT can be used alone or as part of a multi-modality treatment regime with surgery and /or chemotherapy. PBT is complex and requires an understanding of the principles of medical physics, radiobiology, radiation safety, dosimetry, radiation treatment planning, simulation and interaction of radiation with other treatment modalities.

PBT is a treatment that is given with curative intent with long-term local control. Its use can reduce some acute toxicity and more significantly can reduce the long term permanent side effects of treatment and improve the chances of maintaining quality of life. PBT can also be used as part of a dose escalation strategy to increase tumour control, by sparing critical structures. It is typically delivered to patients every weekday, over a number of weeks, depending on the tumour site. Most patients are treated on an outpatient basis.

PBT is a highly complex technology that is still undergoing rapid technical advances. Rigorous quality standards are thus essential. The core group of patients, for whom PBT is indicated, often have complex needs and will require integration with the infrastructure of a major cancer centre, including highly specialist surgery and cancer services. There is a need to accompany PBT with robust outcomes assessment. For all these reasons undertaking PBT within a major cancer centre, linked to an academic oncology and medical physics framework is essential.

3.3 Expected Significant Future Demographic Changes

Paediatric/Teenage & Young Adults

The literature suggests a plateau was reached in childhood cancer incidence rates from the mid-1990s onwards.

The population of the UK has grown faster than most other European countries in the last few years and stands at 63.7M in 2013 and projected to be 66.3M in 2018. Of particular importance for proton radiotherapy is the current and sustained rise in the birth rate with the UK being second only to France in Europe. This means the relative proportion of the population with paediatric cancer extending in the TYA age group, and thus potentially requiring radiotherapy, will rise from past models.

Adults

Changes in the adult demographic accessing the PBT service will be dependent on expansion of the clinical indications in the policies listed above

3.4 Evidence Base

The specification has been developed on the basis of clinical consensus.

There is good clinical evidence for the ability to safely deliver dose escalated radiotherapy with PBT in specific clinical situations to achieve high local control rates and in other areas to avoid unnecessary radiotherapy dose to normal tissues and so reduce the risk of important side effects and risks of radiotherapy induced second malignancy. These latter considerations are particularly important in radiotherapy delivered to paediatric and young persons with cancer, as the cure rates are high. There is evidence of particular sensitivity to certain side effects in younger patients and that they have a huge personal and financial impact in later life.

There is a need to develop a clinical outcomes framework to support the development of a robust and 'research based' evidence base for the use of PBT including clinical trials and studies. There will be an annual research and clinical trials programme for PBT across all ages.

The PBT centre will have the infrastructure to deliver clinical trials and other evaluative commissioning schemes in PBT.

4. Outcomes and Applicable Quality Standards

4.1 Quality Statement – Aim of Service

The aim of the service is to provide high energy proton beam therapy services for adult, teenage and young adult (age 16 – 24 years), and paediatric patients (age < 16 years), to improve cancer outcomes, reduce morbidity arising from treatment and support the patient and family throughout their cancer journey and beyond.

NHS Outcomes Framework Domains

Domain 1	Preventing people from dying prematurely	X
Domain 2	Enhancing quality of life for people with long-term conditions	X
Domain 3	Helping people to recover from episodes of ill-health or following injury	X
Domain 4	Ensuring people have a positive experience of care	X
Domain 5	Treating and caring for people in safe environment and protecting them from avoidable harm	X

4.2 Indicators Include:

No.	Indicator	Data source	Domain(s)	CQC Key Question
Clinical Outcomes				
101	Number of adults referred	Referral Portal	1,2,3,5	effective, safe
102	Number of adults planned	RTDS	1,2,3,6	effective, safe
103	Number of adults treated	RTDS	1,2,3,7	effective, safe
104	Number of teenagers & young adults referred	Referral Portal	1,2,3,5	effective, safe
105	Number of teenagers & young adults planned	RTDS	1,2,3,6	effective, safe
106	Number of teenagers & young adults treated	RTDS	1,2,3,7	effective, safe
107	Number of children referred	Referral Portal	1,2,3,5	effective, safe
108	Number of children planned	RTDS	1,2,3,6	effective, safe
109	Number of children treated	RTDS	1,2,3,7	effective, safe
110	Mean time from decision to treat to first treatment	Self-declaration/ RTDS	1,2,3,5	effective, safe
111	% of children who received general anaesthesia	Self-declaration	1,2,3,5	effective, safe
112	Five year overall survival	Outcomes Dataset	1,2,3,5	effective, safe
113	Five year progression free survival	Outcomes Dataset	1,2,3,5	effective, safe
114	% patients with local tumour control at five years	Outcomes Dataset	1,2,3,5	effective, safe
115	% patients with short-term effects of treatment	Outcomes Dataset	1,2,3,5	effective, safe
116	% patients with long-term effects of treatment	Outcomes Dataset	1,2,3,5	effective, safe
117	Proportion of patients receiving the required number of fractions within the planned length of treatment?	RTDS	1,2,3,5	effective, safe
118	% of equipment uptime	Manufacturer contract monitoring	1,2,3,5	effective, safe
119	number of patients receiving back up treatment,	RTDS & self-declaration	1,2,3,5	effective, safe

120	% patients entered into clinical trials	Local data	1,2,3,5	effective, safe
Patient Outcomes				
201	Patients have a named key worker	Self declaration	3,4	caring responsive
202	There is information for patients and carers	Self declaration	3,4	caring responsive
203	There is accommodation for families and carers	Self declaration	4	caring responsive
204	The service is collecting feedback from patients	Self declaration	4	caring responsive
205	Patient reported outcomes	Outcome dataset	1,2,3,5	effective, safe
Structure & Process				
1	There is a clinical director for the PBT service	Self declaration	1,2,3	well led
2	There is a PBT training programme in place for all staff	Self declaration	1,2,3,5	effective,safe
3	There are contingency plans in place	Self declaration	1,2,3,5	effective,safe
4	There is a quality management system in place	Self declaration	1,2,3,5	effective,safe
5	There is a policy for risk management and error reporting	Self declaration	1,2,3,5	effective,safe
6	There are pathways in place for referral, treatment and follow up.	Self declaration	1,2,3,5	effective,safe
7	There are pathways for interdisciplinary care provision	Self declaration	1,2,3,5	effective,safe
8	There are pathways for referral to supportive therapies	Self declaration	1,2,3,5	effective,safe
9	There are protocols/ guidelines in place	Self declaration	1,2,3,5	effective,safe
10	The service participates in the collection and review of clinical and patient reported outcomes	Self declaration	1,2,3,5	effective,safe, responsive
11	There is involvement in research and clinical trials	Self declaration	1,2,3,5	effective,safe
<p>Detailed definitions of indicators, setting out how they will be measured, is included in schedule 6.</p> <p>4.3 Commissioned providers are required to participate in annual quality assurance and collect and submit data to support the assessment of compliance with the service specification as set out in Schedule 4A-C</p> <p>4.4 Applicable CQUIN goals are set out in Schedule 4D</p>				

5. Applicable Service Standards

5.1 Applicable Obligatory National Standards

The PBT Centre and service must:

- be accredited by relevant national regulatory authorities, including HSE
 - Ionising Radiation Medical Exposure Regulations
 - Ionising Radiation Regulations 99
- ensure protection of children and other vulnerable people in line with national standards
 - (“Safeguarding Vulnerable People in the Reformed NHS: Accountability and Assurance Framework <https://www.england.nhs.uk/wp-content/uploads/2013/03/safeguarding-vulnerable-people.pdf>)
 - Good Practice Guide for Paediatric Radiotherapy ([www.rcr.ac.uk/system/files/publication/field_publication_files/BFCO/\(12\)5_Good_practice_1.pdf](http://www.rcr.ac.uk/system/files/publication/field_publication_files/BFCO/(12)5_Good_practice_1.pdf))
 - Guidance on the provision of paediatric anaesthesia services. (<http://www.rcoa.ac.uk/node/25301>)

5.2 Other Applicable National Standards to be met by Commissioned Providers)

The PBT Centre and service must:

- provide assurance that radiotherapy is delivered according to national and international standards where appropriate and applicable
 - NHS England Service Specification for Radiotherapy (Adult & Paediatric)
 - NHS England Service Specification for Cancer: Chemotherapy (Children, Teenagers and Young Adults)
 - NHS England Service Specification for Cancer: Chemotherapy (Adult)
 - NHS England Service Specification: Level 3 Paediatric Intensive Care
 - Cancer Services for Children & Young People (Q55)
 - Paediatric Intensive Care and associated services (<https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-e/e07/>)
 - Neutropenic Sepsis: Prevention and Management in people with Cancer
 - Good Practice Guide for Paediatric Radiotherapy (RCR/CCLG)
- provide assurance that their services match standards for Radiotherapy, that are consistent with the Cancer Reform Strategy Commitment to develop World Class services and the NHS England Vision for Radiotherapy Services (2014);
- Clinicians and lead staff involved in the management of children with cancer should be members of the CCLG.

5.3 Other Applicable Local Standards

- NHS PBT Service Joint Operational Policy (under development)
- NHS PBT Service Local Operational Policies (under development)

6. Designated Providers (if applicable)

- The Christie NHS Foundation Trust, 550 Wilmslow Road, Manchester M20 4BX (with effect from Autumn 2018)

and

- University College Hospitals London NHS Foundation Trust, former site of the Odeon Cinema, Tottenham Court Road, and the Rosenheim Building, Huntley Street, London NW1 2BU (with effect from Summer 2020)

7. Abbreviation and Acronyms Explained

The following abbreviations and acronyms have been used in this document:

Acronym	Definition
CCGs	Clinical Commissioning Group
CCLG	Children's Cancer & Leukaemia Group
CT	Computed Tomography
Fractions	The full dose of radiation is usually divided into a number of smaller doses called fractions. This allows healthy cells to recover between treatments. Fractions make up a series of treatment sessions that make up a radiotherapy course.
HSE	Health & Safety Executive
MDT	Multi-Disciplinary Team
MRI	Magnetic Resonance Imaging
NHS	National Health Service
ODP	Operating Department Practitioners
OT	Occupational Therapy
PBT	Proton Beam Therapy
POP	Proton Overseas Programme
RCR	The Royal College of Radiologists
RTDS	Radiotherapy Dataset (used for collecting radiotherapy activity)
S2	Direct arrangement between NHS and a healthcare provider in the European Economic Area or Switzerland for funding healthcare
TYA	Teenage and Young Adult
UCLH	University College Hospital London NHS Foundation Trust
UK	United Kingdom

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ANNEX 1 TO SERVICE SPECIFICATION: PROVISION OF SERVICES TO CHILDREN

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

The generic aspects of care:

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

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

Service description/care pathway

All paediatric specialised services have a component of primary, secondary, tertiary and even quaternary elements.

The efficient and effective delivery of services requires children to receive their care as close to home as possible dependent on the phase of their disease.

Services should therefore be organised and delivered through "integrated pathways of care" (*National Service Framework for children, young people and maternity services* (Department of Health & Department for Education and Skills, London 2004).

Interdependencies with other services

All services will comply with *Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies*, Department of Health, 2008.

Imaging

All services will be supported by a three tier imaging network (*Delivering quality imaging services for children* Department of Health, March 2010).

Within the network:

- It will be clearly defined which imaging test or interventional procedure can be performed and reported at each site
- Robust procedures will be in place for image transfer for review by a specialist radiologist, these will be supported by appropriate contractual and information governance arrangements

- Robust arrangements will be in place for Patient transfer if more complex imaging or intervention is required
- Common standards, protocols and governance procedures will exist throughout the network.
- All radiologists and radiographers will have appropriate training, supervision and access to continuing professional development
- All equipment will be optimised for paediatric use and use specific paediatric software

Specialist Paediatric Anaesthesia

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

These competencies include the care of very young/premature babies, the care of babies and children undergoing complex surgery and/or those with major/complex co-morbidity (including those already requiring intensive care support).

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

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

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

References

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

Specialised Child and Adolescent Mental Health Services ("CAMHS")

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

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

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

Applicable national standards e.g. NICE, Royal College

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

- There must be at least two Registered Children's Nurses (RCNs) on duty 24 hours a day in all hospital children's departments and wards.
- There must be an Registered Children's Nurse available 24 hours a day to advise on the nursing of children in other departments (this post is included in the staff establishment of 2 RCNs in total).

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

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

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

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

Providers must have systems in place to gain and review consent from people who use services, and act on them (*Outcome 2a Essential Standards of Quality and Safety, Care Quality Commission, London 2010*). These must include specific arrangements for seeking valid consent from children while respecting their human rights and confidentiality and ensure that where the person using the Services lacks capacity, best interest meetings are held with people who know and understand the person using the service.

Staff should be able to show that they know how to take appropriate consent from children, young people and those with learning disabilities (Outcome 2b) (Seeking Consent: working with children Department of Health, London 2001).

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

- Ensuring that staff and people who use services understand the aspects of the safeguarding processes that are relevant to them.
- Ensuring that staff understand the signs of abuse and raise this with the right person when those signs are noticed.
- Ensuring that people who use services are aware of how to raise concerns of abuse.
- Having effective means to monitor and review incidents, concerns and complaints that have the potential to become an abuse or safeguarding concern.
- Having effective means of receiving and acting upon feedback from people who use services and any other person.
- Taking action immediately to ensure that any abuse identified is stopped and suspected abuse is addressed by:
 - Having clear procedures followed in practice, monitored and reviewed that take account of relevant legislation and guidance for the management of alleged abuse
 - Separating the alleged abuser from the person who uses services and others who may be at risk or managing the risk by removing the opportunity for abuse to occur, where this is within the control of the provider
 - Reporting the alleged abuse to the appropriate authority
 - Reviewing the person's plan of care to ensure that they are properly supported following the alleged abuse incident.
- Using information from safeguarding concerns to identify non-compliance, or any risk of non-compliance, with the regulations and to decide what will be done to return to compliance.

Working collaboratively with other services, teams, individuals and agencies in relation to all safeguarding matters and has safeguarding policies that link with local authority policies.

- Participates in local safeguarding children boards where required and understand their responsibilities and the responsibilities of others in line with the Children Act 2004.
- Having clear procedures followed in practice, monitored and reviewed in place about the use of restraint and safeguarding.
- Taking into account relevant guidance set out in the Care Quality Commission's Schedule of Applicable Publications
- Ensuring that those working with children must wait for a full CRB disclosure before starting work.
- Training and supervising staff in safeguarding to ensure they can demonstrate the competences listed in Outcome 7E of the Essential Standards of Quality and Safety, Care Quality Commission, London 2010

All children and young people who use services must be

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

(Outcome 4I Essential Standards of Quality and Safety, Care Quality

Commission, London 2010)

Key Service Outcomes

Evidence is increasing that implementation of the national *Quality Criteria for Young People Friendly Services* (Department of Health, London 2011) have the potential to greatly improve Patient experience, leading to better health outcomes for young people and increasing socially responsible life-long use of the NHS. Implementation is also expected to contribute to improvements in health

inequalities and public health outcomes e.g. reduced teenage pregnancy and STIs, and increased smoking cessation. All providers delivering services to young people should be implementing the good practice guidance which delivers compliance with the quality criteria.

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

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

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

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

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

There should be age specific arrangements for meeting Regulation 14 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014. These require:

- A choice of suitable and nutritious food and hydration, in sufficient quantities to meet service users' needs.
- Food and hydration that meet any reasonable requirements arising from a Service User's religious or cultural background.

- Support, where necessary, for the purposes of enabling Service Users to eat and drink sufficient amounts for their needs.
- For the purposes of this regulation, “food and hydration” includes, where applicable, parenteral nutrition and the administration of dietary supplements where prescribed.
- Providers must have access to facilities for infant feeding, including facilities to support breastfeeding (*Outcome 5E, of the Essential Standards of Quality and Safety, Care Quality Commission, London 2010*)

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

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

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

For children, these should include specific arrangements that:

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

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

- They are supported to have a health action plan
- Facilities meet the appropriate requirements of the Disability Discrimination Act 2005
- They meet the standards set out in transition: getting it right for young people. Improving the transition of young people with long-term conditions from children's to adult health services. Department of Health, 2006, London.