

E03/S/h

**2013/14 NHS STANDARD CONTRACT  
FOR PAEDIATRIC MEDICINE: PALLIATIVE CARE**

**PARTICULARS, SCHEDULE 2 – THE SERVICES, A - SERVICE  
SPECIFICATIONS**

<b>Service Specification No.</b>	E03/S/h
<b>Service</b>	Paediatric Medicine: Palliative Care
<b>Commissioner Lead</b>	
<b>Provider Lead</b>	
<b>Period</b>	12 months
<b>Date of Review</b>	

**1. Population Needs**

**National/local context and evidence base**

Fraser et al (2012) estimate that there are at least 49,000 children and young people under 19 years in the UK living with a life-limiting or life-threatening condition that may require palliative care services; and that more than 40,000 children (0–19 years) in England in 2009/2010 are living with a life-limiting or life-threatening condition. The prevalence figures for children with life-limiting and life-threatening conditions is greater than those figures previously published by the Association of Children's Palliative Care (ACT) (2009) and the Department of Health (2007). The major difference between the Leeds study and the previously quoted figures is that the Leeds research is the first of its kind to estimate the numbers of children and young people with life-limiting, and those with life-threatening conditions, using national data on children who are currently alive. Previous reports have mainly focussed on death certificate data.

Specialised palliative care for children is provided to children with life-threatening or life-shortening conditions representing an extremely wide range of diagnoses (in excess of 300) and there is an overlap with those with severe disabilities and complex needs. However, a significant proportion of children with palliative care needs (up to 15%) do not have a definitive underlying diagnosis. Children with life-threatening or life-shortening conditions often have multiple complex healthcare needs, including needs related to their underlying condition, as well as palliative care needs. Palliative care services will potentially be needed for all of these children at

any point from diagnosis or recognition, through active treatment, including that aimed at cure, to end of life care and bereavement. But a significant portion of these children will be cured and not all children will have active palliative care needs at any one time. It is therefore not possible to identify provision of Specialised Paediatric Palliative Care for children by diagnosis alone.

Paediatric Palliative Care (PPC) is concerned with providing palliative care to children and young people with either life-limiting or life-threatening conditions who are considered unlikely to reach their 18<sup>th</sup> birthday. PPC may start antenatally and continue beyond a child's 18<sup>th</sup> birthday when supporting transition. It follows the child's illness trajectory, often from diagnosis to end of life care and bereavement.

Consensus definitions of children with palliative care needs, to enable robust and consistent minimum dataset collection, continues to be a challenge. The ACT groups (see Appendix 1) places a child with PPC needs into one group based on their current clinical condition. Over time, the child's health may change and they may move from one group to another or no longer meet the definition at all. Further work on specifically identifying and documenting the types of conditions requiring palliative care continues. However, this in itself also meets with the similar problems of individual patient inter-variability of their specific conditions over time. Even using prognostication by an involved professional to identify children with PPC needs is felt to be inadequate since it is often inaccurate and professionals may be reluctant to give a poor prognosis or identify children as "palliative". Use of the question - would a child live beyond the next year/months/before 18<sup>th</sup> birthday? - may be of use, but there is no published data on this in children. Work around definitions continues.

Hain et al (2010) have compiled a list of over 300 ICD10 diagnoses that have been judged by professionals working in paediatric palliative care to be life-limiting.

The most reliable estimates of children requiring palliative care services in England per year, excluding neonates, shows estimated prevalence and deaths of children and young people (28 days -19years old) as 17,951/yr and 1787/yr, respectively. Therefore for an average strategic health authority (SHA) area, there is a prevalence of 1,795/yr (range: 895-2641) with deaths of 166/yr (range:72-289).

In neonates, overall PPC need is not reported, but on average there are 2,109 neonatal deaths per year for causes likely to require PPC in the UK.

Due to the challenges involved in the collection of reliable pervasive prevalence data and, moreover, distilling need of specialist services, Specialist PPC numbers should only be based loosely on current specialist service activity with recognition of vast gaps in availability of these services per population, increasing complexity of health in the PPC setting and current numbers based on referral rates rather than needs-based.

There are a range of inequalities within the PPC sector, for example hospice provision is driven by charitable sector funding; services are accessed less often by ethnic minorities; access to services can be difficult for those using public transport;

ethnic minorities often have a higher prevalence of certain conditions, and we recognise the influence of social deprivation on prevalence of certain conditions.

## Evidence of Standards of Care

Further detail is also included in section 3.

Available from the Department of Health - [www.dh.gov.uk](http://www.dh.gov.uk)

- Department of Health (2004) “The National Service Framework for children, young people and maternity services”, standard 8, recognises the need for palliative care to be available for those who need it. A range of flexible, sensitive services is available to support families in the event of the death of a child.

Available from Together for Short Lives [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)

- “Standards framework for children's palliative care” (2011). This document sets out the key standards of the care pathway approach to children's palliative care.

Available from Royal College of Paediatrics and Child Health (RCPCH)

- “Bringing networks to life - an RCPCH guide to implementing clinical networks”  
March 2012

## 2. Scope

The service outlined in this specification is for patients ordinarily resident in England\*; or otherwise the commissioning responsibility of the NHS in England (as defined in “Who pays?: establishing the responsible commissioner” and other Department of Health guidance relating to patients entitled to NHS care or exempt from charges).

\* Note: for the purposes of commissioning health services, this EXCLUDES patients who, whilst resident in England, are registered with a GP practice in Wales, but INCLUDES patients resident in Wales who are registered with a GP practice in England

### 2.1 Aims and objectives of service

The aim of the service is to help children and their families achieve a “good” life and a “good” death<sup>1</sup> and barriers should be removed to enable the child and family to lead as “ordinary” a life as possible. Children should be free from distressing symptoms, and children and families should receive support to reduce the emotional and psychological effects of the child or young person's condition through the provision of optimal specialised care and well-co-ordinated services.

<sup>1</sup> “As a society, we fight shy of pondering on death, yet inherent in each of us is a deep desire, both for oneself and for those we love, for a „good“ death. It would be absurd to try to describe that concept more fully beyond saying that everyone in this case knows what it means: not under anaesthetic, not in the course of painful and futile treatment, but peacefully in the arms of those who love [her] most.” – Mr Justice Hedley, High Court Ruling on the Charlotte Wyatt case, 7 October 2004.

## Key objectives

### Lead doctor

Every child and young person should have an identified lead paediatric consultant who will work with the PPC Specialist Team. The child's lead paediatric consultant (this consultant may be the specialist PPC consultant) will have overall clinical responsibility for ensuring that care is coordinated in a holistic manner.

### Identification of all children and young people with palliative care needs.

All children and young people with palliative care needs should be identified as this will allow PPC networks<sup>2</sup> to plan appropriate services and to analyse the gaps between the existing provision. The PPC specialist team should contribute expert advice to this process.

### Assessment of care needs and multi-agency care plan

Every child and young person should receive a multi-agency assessment of their palliative care needs and have an emergency healthcare plan, including a personal resuscitation plan as indicated, agreed with them and which identifies a lead professional/key worker for the family and provides co-ordinated care and support to meet these needs.

### Recognition and planning for end of life care

Every child, young person and family should be supported to agree an end of life plan when the end of life stage is recognised. This should include choice of place of care, place of death and completion of an emergency healthcare plan including personal resuscitation plan as indicated.

### Integrated care

Each child or young person with palliative care needs should have a co-ordinated package of care including a quality assessment; access to key working and appropriate equipment; and measurement of the individual's and their family's experience of the service.

## 2.2 Service description/care pathway

This service specification will provide a consultant-led multi-professional specialist palliative care team, providing a clinical leadership role in planning delivery and evaluation of children's palliative care services across a managed clinical network. It will be led by a medical consultant working at Paediatric Palliative Care Competency

Level 4. It will provide both inpatient and outpatient care for those with life-limiting and life-threatening conditions and will provide the support of the multidisciplinary team. This may be inpatient specialist advisory activity, whilst not necessarily being the admitting consultant, and outpatient care will include care and reviews in the

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<sup>2</sup> Children's palliative care networks are defined by Together for Short Lives as "linked groups of health professionals and organisations from primary, secondary and tertiary care, and social services and other services working together in a co-ordinated manner with clear governance and accountability arrangements".

most appropriate care setting for the child and family including home, school, hospice or other residential short break/ respite unit.

This specification will include the following:

- care within a specialist paediatric unit (both in-patient and out-patient)
- expert advice from a PPC specialist to other paediatric specialists within a referral centre - e.g. paediatric intensive care, oncology, endocrinology, cardiology, urology
- outreach clinics with the specialist and the general paediatrician in the local hospitals, hospices and community settings, including schools
- expert advice from a PPC specialist to the local hospital's general paediatrician caring for the child or, less commonly, to the GP, by letter, telephone, email, face to face or videoconferencing
- expert advice from non-medical multi-disciplinary team members to other healthcare providers e.g. specialist nurses, dieticians, psychologists, pharmacists etc. by letter, telephone, email, videoconferencing or face to face
- visits from members of the multi-disciplinary team to the patient's home and school to provide assessment, training and support to the child, family and other carers.
- transition pathways of care to adult services
- multi-disciplinary meetings

Paediatric palliative care, including specialist paediatric palliative care interventions, usually involve some or all of the following components:

- Assessment of need (e.g. pain assessment)
- Planning of care (e.g. planning for management of increased pain anticipated in association with disease progression)
- Delivery of care (e.g. changing the contents of a syringe driver of medication infused at home for end of life care).

Interventions are likely to fall into one or more of the following categories:

- Communication (breaking bad news/ dealing with collusion)
- Advance care planning
- Emergency healthcare planning
- Clinical ethics
- Co-ordination of care/ key working
- Discharge planning, including rapid discharge to facilitate end of life care in the setting of choice for child and family
- Education (of patient/ family)
- Social support (for the patient, or family including siblings)
- Psychological support (for the patient, or family including siblings)
- Non-drug symptom management techniques such as guided imagery, massage
- Pre-bereavement and bereavement support (for child and family including siblings)
- Pain management
- Symptom management other than pain
- Short break care away from home
- Short break care at home, school or other community setting (including carers)

and care packages)

- End of life care (care in the last hours and days of life) including provision of 24 hours a day, 7 days a week, on call service
- Transition to adult services

The service will provide the full range of specialist paediatric palliative care interventions including complex symptom management, and acute end of life care for both oncological and non-oncological diseases. Examples include management of complex neuropathic pain, and management of other refractory symptoms, and will involve specialist pharmacological knowledge, such as the use of alternative opioids (e.g. methadone), and a wide range of off label and unlicensed use of medicines, conducted within an appropriate framework of clinical governance to ensure safety. The multi-professional service will also be responsive to new developments in the field such as the use of patient controlled analgesia and where appropriate will aim to support their implementation in a timely manner, in as much as they can be supported by local services.

### **Clinical Conditions that are managed by the PPC specialist are described in Appendix 1**

It is anticipated that in the majority of cases Specialist Paediatric Palliative Care will be provided to children who are thought to be in the last few weeks (red), months or years (amber) of life as identified by the Spectrum of Children's Palliative Care Needs.

The service is commissioned to provide care for children as close to home as possible with the local hospital, community services and children's hospice providing as much of the care as possible. This is achieved by creating clinical networks with each local service within the clinical network having at least one clinical lead taking responsibility for children with palliative care needs and the specialist PPC service providing support to the local lead where appropriate. This may include the provision of outreach clinics in the district hospital or children's hospice led by the PPC specialist. Each local service would be required to work within the network and comply with agreed standards with appropriately qualified doctors, nurses and allied health professionals. The place of care will depend on the clinical need and patient choice.

### **Infrastructure of specialist PPC unit**

The PPC specialist may require identified facilities for inpatient and outpatient care, but frequently care is provided in the child's own home. Often facilities and equipment are required at short notice and arrangements may need to be in place to fast-track the provision of such resources e.g. availability of beds within children's hospices to be able to provide care in the place of family choice.

The PPC specialist will be supported by a care team led by a senior nurse (level 7/8).

The multi-disciplinary team essential to support the running of a PPC service will include:

- Medical staff
- Nurses (including those with special expertise in PPC e.g. symptom management)
- Pharmacists
- Social workers
- Psychologists
- Play specialists/youth workers,

Services will be provided in partnership with local services, 24 hours a day, seven days a week according to the identified need of the child and family.

Specialist palliative care telephone advice will be available to network providers 24 hours a day, 7 days a week.

Specialist palliative care telephone advice will be available to patients, parents and carers known to the service and will be available 24 hours a day, 7 days a week.

### **General Paediatric care**

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

### **2.3 Population covered**

It is proposed that there should be at least one PPC specialist service per network, with a maximum of one Specialist Paediatric Palliative Care team for each population of 1 – 2 million people. The geographical area covered, and the population served by each network, does vary and thus the model of service will be slightly different for each region. However, the aim is to develop networks of care, led by the lead specialist centres co-ordinating care with the secondary care, primary care and third sector providers.

The commissioning level for a PPC service should be serving a population of between 1 – 2 million people. York Economics Consortium (Lowson et al 2007) recognises that the relatively small numbers of children and young people within a population of 250,000, and the specialist nature of the services, points to the advisability of planning these services for a larger population of at least 1 million, or even at a SHA level (i.e. 4 million). The configuration of Specialist Palliative Care Services must take into account location of relevant specialist services such as paediatric intensive care units (PICU) and cancer centres as well as patient flows.

Children, up to the day before their 19<sup>th</sup> birthday with life-limiting/life-threatening conditions will have access to this service. However, young people will usually be transferred to adult services prior to their 18<sup>th</sup> birthday.

Palliative care services, including Specialist Paediatric Palliative Care should be accessible to babies, children and young people with:

- Critical illness on neonatal and paediatric intensive care units
- Cancer
- Severe congenital heart disease and cardiomyopathies
- Muscular dystrophies and spinal muscular atrophy
- Spastic quadriplegic cerebral palsy
- Severe inborn errors of metabolism
- Multiple congenital malformations
- Significant chromosomal anomalies
- Some children with cystic fibrosis
- Some children who are technology-dependent
- Some children with undiagnosed conditions which are clearly life-shortening.

These children must be included even if they do not have a diagnostic label

## 2.4 Any acceptance and exclusion criteria

Referral to specialised PPC services will include consultant to consultant referrals and will be within locally agreed protocols from GP or other services.

Transition pathways will be in place to ensure safe transfer to adult services.

The aim is for planned care rather than crisis management and early notification of possible referrals is preferred

Support provided for urgent referrals (<24 hours: primarily telephone advice for end of life care) may be limited to telephone advice only depending on the location of the patient at referral.

## 2.5 Interdependencies with other services

There is a need for close working between the PPC specialist and critical care services as well as other specialised paediatric services including paediatric specialised surgery, paediatric intensive care, nephrology, cardiology, neurology, haematology, immunology, respiratory, endocrinology, gastroenterology (including hepatology), ENT, neonatology, orthopaedics and rheumatology services.

The following should therefore be considered as critical interdependences:

- Specialised Paediatric Cancer Services (paediatric oncology, malignant haematology and cancer surgery services)
- Specialised Paediatric Cardiology and Cardiac Surgery Services
- Specialised Paediatric Gastroenterology, Hepatology and Nutritional Support Services
- Specialised Paediatric Intensive Care Services
- Specialised Neonatal Care Services
- Specialised Paediatric Neurosciences Services
- Specialised Paediatric Renal Services
- Specialised Paediatric Respiratory Services



- Specialised Paediatric Surgery Services

Specialist Paediatric Palliative Care Networks including representation of all core palliative care services and universal services must also be considered as critical interdependencies.

Access to essential support services must include support from the full multi-disciplinary team including nurses, pharmacists, social workers, psychologists, play specialists/youth workers and bereavement services.

### 3. Applicable Service Standards

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

A series of standards are set out in the ACT Care Pathways and are detailed within the “Together for Short Lives” Standards framework for children’s palliative care. This document sets out the key standards of the care pathway approach to children’s palliative care.

Standards also reflects clinical relationships in “Commissioning safe and sustainable specialised paediatric services: a framework of critical inter- dependencies” as well as standards in “Bringing Networks to Life- An RCPCG guide to implementing Clinical networks.”<sup>3</sup>

Specialist paediatric palliative care services are most sustainable and cost effective when they are planned and commissioned across total populations of at least 1-1.5 million<sup>4,5,6</sup>.

Paediatric palliative care is best provided through a managed clinical network with much of the direct care received by children being delivered through core children’s palliative care services<sup>7</sup> and support being offered from specialist paediatric palliative care teams for the most complex cases, when needed.

#### References to further standards

1. Standards framework for children's palliative care (2011). Together for Short Lives.
2. Commissioning Safe and Sustainable Specialised Paediatric Services - A Framework of Critical Inter-Dependencies. Royal Colleges of Paediatrics &
3. Child Health, Anaesthetics, Physicians, Surgeons and Nursing and the Association of Chief Children’s Nurses, 2008. Supported by the Department of Health and the National Specialised Commissioning Group.
4. Bringing Networks to Life- An RCPCG Guide to Implementing Clinical Networks
5. Palliative Care Services for Children and Young People, Department of Health, Craft & Killen, 2007
6. Needs based palliative care commissioning for children, young people and their families: A Guide. ACT, April 2011

7. The Palliative Care Funding Review, Final Report, July 2011; Tom Hughes-Hallet, Prof Alan Craft, Catherine Davies
8. [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk) Children's Palliative Care Networks, Association for Children's Palliative Care (ACT) 2009

#### 4. Key Service Outcomes

##### General outcomes

- That children, young people and their families are able to engage in discussions around their child's future care and develop anticipatory care plans, including end of life plans as appropriate, and that these plans are delivered effectively.
- That children, young people and their families have the information they require to make decisions about end of life and that they receive high quality care when they need it.
- That symptoms experienced by children and young people are recognised and well managed so that, as far as possible, symptoms are controlled and the child is able to lead as normal life as possible including attending school.
- All children and young people with palliative care needs receive specialist respite care and short breaks provision as part of their statutory continuing care package.

#### ANNEX 1 TO SERVICE SPECIFICATION: PROVISION OF SERVICES TO CHILDREN

##### Aims and objectives of service

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

The generic aspects of care:

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

- Children are admitted to hospital only if the care they require cannot be as well provided at home, in a day clinic or on a day basis in hospital.
- Children requiring admission to hospital are provided with a high standard of medical, nursing and therapeutic care to facilitate speedy recovery and minimise 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

## **Imaging**

All services will be supported by a three-tier imaging network (“Delivering quality imaging services for children”, Department of Health 13732 March, 2010). Within the network;

- it will be clearly defined which imaging test or interventional procedure can be performed and reported at each site
- robust procedures will be in place for image transfer for review by a specialist radiologist, these will be supported by appropriate contractual and information governance arrangements
- robust arrangements will be in place for patient transfer if more complex imaging or intervention is required
- common standards, protocols and governance procedures will exist throughout
- 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.<sup>1</sup> 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) training<sup>2</sup> and should maintain the competencies so acquired<sup>3</sup> \*. 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 magnetic resonance imaging (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. Guidelines for providing anaesthetic services (GPAS) Paediatric anaesthetic services. Royal College of Anaesthetists (RCoA) 2010  
[www.rcoa.ac.uk](http://www.rcoa.ac.uk)
2. Certificate of completion of training (CCT) in Anaesthesia 2010
3. Continuous professional development (CPD) matrix level 3

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

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

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

- Facilities and environment – essential Quality Network for In-patient CAMHS (QNIC) standards should apply  
(<http://www.rcpsych.ac.uk/quality/quality accreditation/audit/qnic1.aspx>)
- Staffing profiles and training - essential QNIC standards should apply.
- The child/ young person's family are allowed to visit at any time of day taking account of the child / young person's 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. National Institute of Health and Care Excellence (NICE), Royal Colleges**

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 two 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 for children and young people, including in relation to specific anaesthetic and surgical procedures for children, taking account of guidance from relevant expert or professional bodies (Outcome 14g *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010).

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

appropriate consent from children, young people and those with learning disabilities (Outcome 2b) (*Seeking Consent: working with children* Department of Health, London 2001).

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

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

All children and young people who use services must be:

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

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

### Key Service Outcomes

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

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

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

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

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

are contacted if necessary.

- **A18.10** There are written procedures for the assessment of pain in children and the provision of appropriate control.

All hospital settings should meet the Standards for the Care of Critically Ill Children

(Paediatric Intensive Care Society, London 2010).

There should be age specific arrangements for meeting Regulation 14 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010. These require:

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

All paediatric patients should have access to appropriately trained paediatric trained dietitians, 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 1995
- they meet the standards set out in Transition: getting it right for young people. Improving the transition of young people with long-term conditions from children's to adult health services. Department of Health, 2006, London

## APPENDIX 1

Conditions managed by PPC specialist in partnership with other specialist and generalist services include:

Palliative care services, including Specialist Paediatric Palliative Care should be accessible to babies, children and young people with

- Critical illness on neonatal and paediatric intensive care units
- Cancer
- Severe congenital heart disease and cardiomyopathies
- Muscular dystrophies and spinal muscular atrophy
- Spastic quadriplegic cerebral palsy
- Severe inborn errors of metabolism
- Multiple congenital malformations
- Significant chromosomal anomalies
- Some children with cystic fibrosis
- Some children who are technology-dependent
- Children who have no overarching diagnosis but clearly have a life shortening condition

Four broad groups of life-threatening and life-limiting conditions may be delineated. Categorisation is not easy and the examples used in the table below are not exclusive. Diagnosis is only part of the process; the spectrum of disease, severity of disease and subsequent complications and the needs of and impact on the child and family need to be taken into account. The table below describes the different categories of conditions which may affect children and young people.

<b>Category 1</b>	<p><b>Life-threatening conditions for which curative treatment may be feasible but can fail.</b></p> <p>Where access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of that threat to life.</p> <p>On reaching long term remission or following successful curative treatment there is no longer a need for palliative care services.</p> <p>Examples: cancer, irreversible organ failures of heart, liver, kidney.</p>
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<b>Category 2</b>	<b>Conditions where premature death is inevitable.</b>  Where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.  Examples: cystic fibrosis, Duchenne muscular dystrophy.
<b>Category 3</b>	<b>Progressive conditions without curative treatment options</b>  Where treatment is exclusively palliative and may commonly extend over many years  Examples: Batten disease, mucopolysaccharidosis
<b>Category 4</b>	<b>Irreversible but non-progressive conditions causing severe Disability, leading to susceptibility to health complications and likelihood of premature death.</b>  Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs and a high risk of an unpredictable life-threatening event or episode.

**ACT 2009**

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