

**NHS STANDARD CONTRACT  
PAEDIATRIC MEDICINE: RHEUMATOLOGY**

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

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

## 1. Population Needs

### 1.1 National/local context and evidence base

#### National context:

The prevalence of the spectrum of paediatric rheumatological diseases varies depending on factors such as local demography and ethnicity. Many of the diseases are rare (<1 in 10,000 incidence). Even the more common Juvenile Idiopathic Arthritis [JIA] has an incidence of 1/10,000 and a prevalence of 1:1000; many of the subtypes of JIA are very rare. Other conditions such as juvenile dermatomyositis [JDM] and auto-inflammatory syndromes are extremely rare (<<1 in 10,000).

Conditions managed by the specialist paediatric rheumatology team include inflammatory and non-inflammatory rheumatic conditions (ICD10- and OPCS 4.5 Codes) including JIA, Juvenile Systemic Lupus Erythematosus [JSLE], JDM, vasculitis as well as pain syndromes, unexplained fevers, complex multisystem disease, uveitis and medically unexplained physical symptoms with rheumatological manifestations and associations. In addition osteogenesis imperfecta, juvenile idiopathic osteoporosis, metabolic bone disease and auto-inflammatory conditions are managed by specialist rheumatology teams. The full list of conditions is in Appendix 1.

Rheumatic diseases are an important cause of disability in children and young people. Without appropriate therapy, some conditions (such as JSLE, severe systemic onset JIA and many forms of vasculitis) can be fatal. JIA rarely has life threatening complications, but this and other conditions, e.g., uveitis and scleroderma, can be associated with a lifetime of disability. Uveitis can cause

permanent visual loss.

Prompt access to specialist care is key to optimising clinical outcomes. Inadequate treatment causes worse clinical outcomes with morbidity (e.g. joint damage, blindness, osteoporosis) and potential mortality, long-term physical and psychosocial harm to the child, considerable impact on families and ultimately has long-term consequences.

Evidence base:

Available from British Society for Paediatric and Adolescent Rheumatology;  
[www.bspar.org.uk](http://www.bspar.org.uk)

- 'Position statement on professionals working in paediatric rheumatology' Baildam E, Davidson J. *Rheumatology* (Oxford). 2008 Jun; 47(6):743-4. This details the minimum requirements for a specialist team
- 'Standards of care for children and young people with JIA'. Davies K, et al *Rheumatology* 2010 (Oxford) 49: 1406-1408
- 'Autologous haematopoietic stem cell rescue for severe rheumatic disease in children and young people: guidance for BSPAR members', Foster HE et al *Rheumatology* (Oxford). 2006 Dec; 45(12):1570-1.

Available from Arthritis Research UK – [www.arthritisresearchUK.org](http://www.arthritisresearchUK.org)  
National Institute of Health Research (NIHR) Arthritis Research UK / Medicines for Children Research Network Paediatric Rheumatology Clinical Studies Group Strategy (2011)

### **National standards and guidelines**

- Available from Royal College of Paediatrics and Child Health (RCPCH)
- 'Bringing Networks to Life - An RCPCH guide to implementing Clinical Networks' March 2012. Available from Department of Health - [www.dh.gov.uk](http://www.dh.gov.uk)
- Department of Health (2006) 'The musculoskeletal services framework; a joint responsibility: doing it differently'
- Department of Health (2004) 'National Service Framework for Children, Young People and Maternity Services' (key issues for primary care: core standards; standard for disabled children and young people and those with complex health needs)
- Map of Medicine – Juvenile Idiopathic Arthritis 2010. M Friswell , E Hutchinson, H Venning, AG Cleary , HE Foster  
[http://healthguides.mapofmedicine.com/choices/map/juvenile\\_idiopathic\\_arthritis1.html](http://healthguides.mapofmedicine.com/choices/map/juvenile_idiopathic_arthritis1.html)
- Department of Health; UK Plan for Rare Diseases (2012)

Available from the National Institute of Health and Clinical Excellence -  
[www.nice.org.uk](http://www.nice.org.uk)

- National Institute for Health and Care Excellence (NICE) (2002) 'Etanercept for the treatment of juvenile idiopathic arthritis,' NICE Technology Appraisal, TA35

Available from the Royal College of Nursing - [www.rcn.org.uk](http://www.rcn.org.uk)

- RCN (2009) 'Assessing, managing and monitoring biological therapies for inflammatory arthritis' Publication code: 001 984
- RCN (2007) 'Adolescent transition care: guidance for nurses' Publication code: 002 313
- RCN (2004) 'Administering subcutaneous methotrexate for inflammatory arthritis: guidance for nurses' Publication code: 002 269

## 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

#### Aims:

To provide optimal specialist clinical care for children and young people with rheumatic disease and for such care to be patient and family focussed.

#### Objectives:

- To correctly diagnose the condition in a timely and efficient manner.
- To achieve and maintain remission of disease, minimise disability and deformity, and preserve normal physical, social, and emotional growth and development.
- To optimise patient related outcomes, by providing the most appropriate care for children and young people with rheumatic diseases.
- To ensure that there is a sufficient, skilled and competent multi-disciplinary workforce to manage children and young people with rheumatic diseases.
- Ensure that all children and young people have timely access to services for appropriate diagnosis and on-going care which minimises travelling and disruption to family life.
- To ensure that children and young people have their health, education and any social care plans coordinated.
- To ensure children and young people with rheumatic conditions are treated in line with national guidelines and agreed local pathways.
- To ensure that children and young people have optimal opportunity to take part in clinical research and clinical trials as part of National Institute for Health Research (NIHR) portfolio activity.
- To ensure optimal age-appropriate care and transition into adult services.

## 2.2 Service description/care pathway

- Many conditions require specialist multi-disciplinary care, and the specialist team will work with local teams to enhance early diagnosis and delivery of optimal clinical care close to the patient's home where possible. Models of delivery are outlined in the RCPCH guidance, 'Bringing Networks to Life' 2012.
- There will be a robust system for information sharing across a pathway of care and shared care guidelines and protocols to deliver good practice. Management for many children and young people requires specialist transitional care into adult rheumatology care involving specialist multi-disciplinary teams working together from paediatric, adolescent and adult rheumatology.

### Investigations

- Diagnostic services include both making a diagnosis of a rheumatological illness and, in other cases, excluding a rheumatological disease in patients with complex symptoms.
- The service will provide diagnostic services that require rapid access to a variety of specialist paediatric diagnostic services to underpin the clinical services including laboratory and radiological investigations and often requiring expert interpretation. Where appropriate, invasive or difficult procedures (such as MRI, bone marrow) general anaesthesia, paediatric anaesthesia and appropriate paediatric facilities and staff will be available. Investigations performed by specialists (for diagnosis and monitoring of disease) include musculoskeletal ultrasound, although this is performed by radiologists in some centres.
- Specialist teams will work within effective triage services to facilitate early recognition and access to care; these may include primary or community care as well as secondary care (e.g. accident and emergency, orthopaedics, general paediatrics). Education and training of staff working with children to recognise clinical features suggestive of rheumatic disease is key to early identification and diagnosis and will be an integral part of clinical networking (RCPCH 'Bringing networks to life' 2012).

### Interventions

- All drugs initiated, prescribed, delivered and monitored in specialist care
- Drugs include off-license and licensed indications of disease-modifying anti-rheumatic drugs (such as Methotrexate), biologics, cytotoxics, novel
- therapies, intravenous (IV) steroids, immunoglobulin, plasma exchange or IV bisphosphonates. Many treatments require paediatric day case facilities.
- Some treatments will be available as part of clinical trials (NIHR Portfolio)\*. The use of many of these drugs is increasing in specialist care.
- Procedures include joint injections ([injecting corticosteroids] – these require general anaesthetic or conscious sedation or (IV) sedation and paediatric day case facilities.
- Home care delivery programmes (Methotrexate and some biologics)
- Opportunity for children and young people and their families to take part in clinical trials (BSPAR) standards of care. Specialist teams will link with NIHR

clinical research networks (RCN's) to facilitate research infrastructure support.

### **The specialist multidisciplinary team (MDT)**

The specialist MDT is defined (BSPAR Position Statement,2008) and (Standard of Care (2010)) and as a minimum constitutes: consultant paediatric rheumatologists specialist nurses, physiotherapist(s), occupational therapist(s), ophthalmologist, pharmacist, podiatrist, orthotist with and access to dentist / orthodontist, dietician, clinical psychologist / psychiatrist, pain team and hospital play specialist, teacher, social worker and administrative support. The specialist team will have close links with adult rheumatology teams for transitional care.

The number of personnel per specialist team is influenced by the population size and geographical coverage (RCPCH 'Bringing Networks to Life' 2012). The team will be required to deliver a service, 24 hours /seven days a week and meet the BSPAR Standards of Care in order to provide advice and care as laid down by the standards. As a minimum, and extrapolated from BSR guidance for adult rheumatoid arthritis, there will be one consultant paediatric rheumatologist, two nurse specialists and one physiotherapist and occupational therapist, per 200,000 children.

### **Transitional care**

Specialised paediatric rheumatology teams will provide transitional care to facilitate transfer and on-going care in adult rheumatology. Transitional care planning will involve adult rheumatology teams and local hospitals under a shared care arrangement (RCPCH 'Bringing networks to life' 2012).

### **Long-term management**

For many children and young people with rheumatic disease (at least 1/3 of children with JIA and most children with JSLE or JDMS), there is need for long-term care within adult rheumatology teams. There may also be need for specialist orthopaedic intervention.

### **Normal hours of operation are:**

- Inpatient services (including intensive care) - 24 hours / seven days a week
- Day case / short stay: 5 days a week Monday to Friday
- Outpatient clinics: 5 days a week Monday to Friday; including outreach activity
- A consultant paediatric rheumatologist will be available to give advice 24/7 including new patients and acute referrals of on-going problems.

### **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**

Current guidance is that there should be one specialist paediatric rheumatology centre per 500,000 total population. This guidance, however, predates the era of

biologics and current practice of more aggressive management (BSPAR Standards of Care). In line with BSR guidance for adult rheumatoid arthritis, it is more likely that the number of specialist centres will increase (see 2.2). There are currently 12 specialist paediatric rheumatology centres in England and population coverage is patchy. More centres are likely to evolve pending local populations, geography and local expertise.

## **2.4 Any acceptance and exclusion criteria**

### **Acceptance criteria**

Specialist services play a key role in the diagnosis of conditions listed in Appendix 1 for rheumatology as well as;

- Investigation of prolonged fever, rash, arthritis, weakness, weight loss, anaemia, raised inflammatory markers or generalised malaise, fatigue or anorexia that may be due to rheumatological disease.
- Assessment and management of chronic medically unexplained pain or loss of function, or complex chronic fatigue, including difficult child protection cases presenting with rheumatological features. These children and young people have the potential to remain under the care of specialist paediatric rheumatology care for long term management and will be managed using
- non-medical approaches and by professionals with specific expertise.
- Exclusion of a rheumatological diagnosis in children and young people with musculoskeletal pain due to non-inflammatory diseases, including hypermobility and osteochondroses (if associated with persistent and disabling symptoms).

Referral criteria through guidelines and protocols with local paediatric services, based on severity, complexity and rarity of conditions and triage services with clinicians appropriately trained in paediatric rheumatology.

### **Pathways may include:**

- Acute referral from A&E department, general paediatric service or other specialty service e.g. orthopaedics, ophthalmology, renal
- GP or paediatric referral for initial assessment, diagnosis, specialist intervention or shared care based on agreed local protocols and guidelines

Exclusions to the service will be specified in shared care guidance and protocols along with the upper age limit of up to 19th birthday

### **Discharges from the service;**

- Children and young people transferred to adult rheumatology as part of transitional care and determined by shared care guidelines and protocols based on individual needs and from the age of 16 years.
- Children and young people with stable complex or less challenging rheumatic disease to be managed by local paediatric providers or primary care with shared care guidelines, protocols and clear indicators for re-referral back to the specialist team.

Discharge processes ensure timely and appropriate communications with robust IT support.

## 2.5 Interdependencies with other services

- Many children and young people with rheumatic disorders may have involvement of more than one system. Interface with other specialised services is very important as detailed in the Department of Health Report 2008 'Commissioning a Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies'.
- Key interdependencies include paediatric intensive care, renal services, immunology and infectious diseases, paediatric and adult orthopaedics, emergency care, haematology and neurology. In addition all specialist paediatric rheumatology requires close working arrangements with paediatric radiology, chemical pathology and clinical genetics services for diagnosis and management.
- There will be partnership with children and young people, their families, as well as the public, including the voluntary sector and charities, in order to optimise outcomes that are focussed on children and young people and their families.
- There will be access to 'supra-regional' services from the specialist centre (these include nationally commissioned services with national guidance and include stem cell transplantation service for severe rheumatic disease (including JIA) in children and young people, complex Ehlers Danlos service and chronic pain services.

## 3. Applicable Service Standards

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

The service will be provided from a children and young people's facility with equipment to national standards and co-location with other paediatric specialties.

(Available from British Society for Paediatric and Adolescent Rheumatology; [www.bspar.org.uk](http://www.bspar.org.uk)).

- Specialist services in the clinical network will provide / deliver clinical care including response times and access to appropriately trained clinicians in the specialist team in line with national standards and guidance as listed below:
  - BSPAR 'Position statement on professionals working in paediatric rheumatology' Baildam E, Davidson J. Rheumatology (Oxford). 2008 Jun; 47(6):743-4. This details the minimum requirements for a specialist team
  - 'BSPAR Standards of care for children and young people with JIA', Davies

- K, et al Rheumatology 2010 (Oxford) 49: 1406-1408.
- 'Autologous haematopoietic stem cell rescue for severe rheumatic disease in children and young people: guidance for BSPAR members', Foster HE, et al Rheumatology (Oxford). 2006 Dec; 45(12):1570-1.

Available from Arthritis Research UK –[www.arthritisresearchuk.org](http://www.arthritisresearchuk.org)

- NIHR Arthritis Research UK / Medicines for Children Research Network Paediatric Rheumatology Clinical Studies Group Strategy (2011)

### **National standards and guidelines**

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

- 'Bringing Networks to Life - An RCPCH guide to implementing Clinical Networks' March 2012

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

- Department of Health (2006) 'The musculoskeletal services framework - a joint responsibility: doing it differently'
- Department of Health (2004) 'National service framework for children, young people and maternity services' (documents include key issues for primary care; core standards; standard for disabled children and young people and those with complex health needs).
- Department of Health (2008) 'Commissioning a Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter- Dependencies'.

Available from the National Institute for Health and Care Excellence - [www.nice.org.uk](http://www.nice.org.uk)

- NICE (2002) 'Etanercept for the treatment of juvenile idiopathic arthritis,' Technology Appraisal TA35.
- NICE (2011) 'Tocilizumab for the treatment of systemic juvenile idiopathic arthritis,' Technology Appraisal TA238.

Available from the Royal College of Nursing - [www.rcn.org.uk](http://www.rcn.org.uk)

- RCN (2009) 'Assessing, managing and monitoring biological therapies for inflammatory arthritis' Publication code: 001 984
- RCN (2007) 'Adolescent transition care: guidance for nurses' Publication code: 002 313
- RCN (2004) 'Administering subcutaneous methotrexate for inflammatory arthritis: guidance for nurses' Publication code: 002 269



## 4. Key Service Outcomes

### General

- To correctly diagnose the condition in a timely and efficient manner
- To achieve and maintain remission of disease, thus optimising normal growth and development, minimising disability and deformity, and preserve normal physical, social and emotional growth and development
- To minimise morbidity and mortality and to optimise patient outcomes, by providing the most appropriate care for children and young people with rheumatic diseases
- To ensure that there is a sufficient, skilled and competent multi-disciplinary workforce to manage children and young people with rheumatic diseases.
- To ensure shared care and clinical networks deliver good specialist care as close as possible to people's homes
- Ensure that all children and young people have timely access to services for appropriate diagnosis and on-going care which minimises travelling and disruption to family life
- To ensure that children and young people have their healthcare and any social care plans coordinated
- To ensure that children and young people with rheumatic conditions are treated in line with national guidelines and agreed local pathways
- To ensure that children and young people have optimal opportunity to take part in clinical research and clinical trials as part of NIHR portfolio activity
- To ensure optimal age-appropriate care and transition into adult services.
- To collect data on defined conditions into secure databases for audit purposes
- To conduct regular local and national audits of service performance based on national guidance and standards of care

### Specific

- Prompt assessment by specialist teams with back up from paediatric sub specialties
- Education and training to ensure that the workforce working with children and young people with rheumatic disease have optimal skills and training
- Structured referral pathways, shared care guidelines and protocols (NICE, BSPAR, RCN).
- Advice and support (telephone/digital) by specialist MDTs for families and for health care teams in other hospitals within the clinical network (BSPAR, RCN)
- Robust information sharing and process for clinical governance(BSPAR).
- Compliance with guidelines for Methotrexate/biologics and long term surveillance (RCN, NICE, BSPAR).
- Facilitate participation in NIHR Portfolio clinical trials and clinical research to inform good practice and optimise clinical outcomes (BSPAR)
- Home and school visits to facilitate the child living at home / in the community

- Access to home delivery/administration of treatment with support and training to families (RCN,BSPAR)
- Consumer (public/patient/family) and charities/voluntary sector involvement in service development and evaluation
- Access to other networks/services, as necessary including nationally commissioned services
- Transitional services to adult rheumatology care

## **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 (Health Service Circular (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 Interdependencies' – 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 the network
- All radiologists, and radiographers will have appropriate training, supervision and access to continuing professional development (CPD)
- 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

- Guide for Providing Anaesthetic Services (GPAS) Paediatric anaesthetic services. Royal College of Anaesthetists (RCoA) 2010 [www.rcoa.ac.uk](http://www.rcoa.ac.uk)
- Certificate for Completion of Training (CCT) in Anaesthesia 2010
- 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/inpatient settings is different to the age profile for paediatric units in that it is predominantly adolescents who are admitted to specialised CAMHS inpatient 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/inpatient 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,accreditationaudit/qnic1.aspx>)
- Staffing profiles and training - essential QNIC standards should apply.
- The child/ young person's family is 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 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 which admits inpatients must have appropriate medical cover at all times taking account of guidance from relevant expert or professional bodies (National Minimum Standards for Providers of Independent Healthcare, Department of Health, London 2002). 'Facing the Future' Standards, Royal College of Paediatrics and Child Health.
- Staff must carry out sufficient levels of activity to maintain their competence in caring for children and young people, including in relation to specific anaesthetic and surgical procedures for children, taking account of guidance from relevant expert or professional bodies (Outcome 14g 'Essential Standards of Quality and Safety', Care Quality Commission, London 2010).
- Providers must have systems in place to gain and review consent from people who use services, and act on them (Outcome 2a 'Essential Standards of Quality and Safety', Care Quality Commission, London 2010). These must include specific arrangements for seeking valid consent from children while respecting their human rights and confidentiality and ensure that where the person using the service lacks capacity, best interest meetings are held with people who know and understand the person using the service. Staff should be able to show that they know how to take appropriate consent from children, young people and those with learning disabilities (Outcome 2b) ('Seeking consent: working with children', Department of Health, London 2001).
- Children and young people must only receive a service from a provider who takes steps to prevent abuse and does not tolerate any abusive practice should it occur.

Outcome 7 'Essential Standards of Quality and Safety', Care Quality Commission, London 2010, defines the standards and evidence required from providers in this regard). Providers minimise the risk and likelihood of abuse occurring by:

- ensuring that staff and people who use services understand the aspects of the safeguarding processes that are relevant to them.
- ensuring that staff understand the signs of abuse and raise this with the right person when those signs are noticed.
- ensuring that people who use services are aware of how to raise concerns of abuse.
- having effective means to monitor and review incidents, concerns and complaints that have the potential to become an abuse or safeguarding concern.
- having effective means of receiving and acting upon feedback from people who use services and any other person.

- taking action immediately to ensure that any abuse identified is stopped and suspected abuse is addressed by:
  - having clear procedures followed in practice, monitored and reviewed that take account of relevant legislation and guidance for the management of alleged abuse
  - separating the alleged abuser from the person who uses services and others who may be at risk or managing the risk by removing the opportunity for abuse to occur, where this is within the control of the provider
  - reporting the alleged abuse to the appropriate authority
  - reviewing the person's plan of care to ensure that they are properly supported following the alleged abuse incident
- using information from safeguarding concerns to identify non-compliance, or any risk of non-compliance, with the regulations and to decide what will be done to return to compliance.
- working collaboratively with other services, teams, individuals and agencies in relation to all safeguarding matters and has safeguarding policies that link with local authority policies.
- participates in local safeguarding children boards where required and understand their responsibilities and the responsibilities of others in line with the Children Act 2004
- having clear procedures followed in practice, monitored and reviewed in place about the use of restraint and safeguarding.
- taking into account relevant guidance set out in the Care Quality Commission's Schedule of Applicable Publications
- ensuring that those working with children must wait for a full Criminal Records Bureau (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) has 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
- that providers must have access to facilities for infant feeding, including facilities to support breastfeeding (Outcome 5E, of the 'Essential Standards of Quality and Safety', Care Quality Commission, London 2010)

All paediatric patients should have access to appropriately trained paediatric trained dieticians, physiotherapists, occupational therapists, speech and language therapy, psychology, social work and CAMHS services within nationally defined access standards. All children and young people should have access to a professional who can undertake an assessment using the Common Assessment Framework and access support from social care, housing, education and other agencies as appropriate.

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

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

Many children with long term illnesses have a learning or physical disability.

Providers should ensure that:

- they are supported to have a health action plan
- facilities meet the appropriate requirements of the Disability Discrimination Act 1995
- they meet the standards set out in 'Transition: getting it right for young people. Improving the transition of young people with long-term conditions from children's to adult health services'. Department of Health Publications, 2006, London



## Appendix 1

Connective tissue diseases including systemic lupus erythematosus, juvenile dermatomyositis, mixed connective tissue diseases, scleroderma – systemic and localised/linear morphoea, Sjogren's syndrome.

Patients receiving immunosuppressive, cytotoxic or biologic therapies Familial periodic fever syndromes

Reactive (post infectious) arthritis

Diagnostic evaluation and long-term management of chronic inflammatory arthritis to include:

- JIA and its subtypes (i.e. oligo articular (persistent or extended), Polyarticular (rheumatoid factor positive or negative) JIA, Systemic onset JIA
- Psoriatic and enthesitis related arthritis
- Other arthritis associated with inflammatory bowel disease or chronic inflammatory diseases

### Chronic vasculitis:

- Polyarteritis nodosa
- Atypical Kawasaki disease
- Atypical Henoch Schonlein purpura
- Wegner's granulomatosis
- Behcet's syndrome
- Takayasu's arteritis
- Hypocomplementemic vasculitis or hypersensitivity vasculitis
- Cerebral vasculitis
- Post-infectious vasculitis
- Anti-phospholipid syndromes Acute rheumatic fever Sarcoidosis
- Lyme disease with arthritis
- Chronic recurrent multifocal osteomyelitis Auto-inflammatory syndromes
- Post-infectious arthritis Relapsing polychondritis Uveitis
- Osteoporosis

Genetic syndromes associated with stiff joints or severe hypermobility e.g. Ehlers Danlos and Marfan's syndrome

Joint disease associated with other medical diagnoses e.g. inflammatory bowel disease, cystic fibrosis, complex cyanotic heart disease, Down's syndrome, immunodeficiency, neoplasm, infectious disease, endocrine disorders, genetic and metabolic disease, post transplantation, and arthritis associated with birth defects.

### Major pain syndrome:

- Erythromelalgia
- Fibromyalgia
- Reflex sympathetic dystrophy and complex regional pain syndromes

- Cold induced injury
- Over use syndromes

**Surgery**

Children with juvenile idiopathic arthritis with cervical spine involvement will require specialised paediatric surgery and anaesthesia services.

Interim for Adoption from 01/10/13