

E03/S/a

**2013/14 NHS STANDARD CONTRACT FOR PAEDIATRIC MEDICINE: RENAL
PARTICULARS, SCHEDULE 2 – THE SERVICES, A – SERVICE
SPECIFICATION**

Service Specification No.	E03/S/a
Service	Paediatric Medicine: Renal
Commissioner Lead	
Provider Lead	
Period	12 months
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

Specialised paediatric renal services provide care for a wide variety of conditions. Many children with uncomplicated general nephrological conditions - e.g. simple urinary tract infection or steroid responsive nephrotic syndrome, may be managed by general paediatricians in local hospitals without reference to a specialist paediatric nephrologist at the specialist renal centre. Some children develop complications of common conditions or have rare conditions benefiting from specialist expertise, whilst others require specialist diagnostic and therapeutic procedures including dialysis and transplantation that can only be provided by a specialist renal centre. Children requiring the more complex paediatric nephrology services are treated at the 10 specialist renal centres in England, all of which provide both haemodialysis and peritoneal dialysis. Eight of these centres also provide paediatric renal transplantation. Children with renal disease often have multi-system problems and require co-location with other specialties as detailed in *Commissioning Safe and Sustainable Specialised Paediatric Services - A framework for critical Inter-dependencies*.

Individual renal diseases are rare in children.

Incidence

The incidence varies according to the condition, for example:

- chronic kidney disease (dialysis and transplant): 8.1 per million age related population (pmarp) in children pa <16 yrs* (reference 14th UK Renal Registry report July 2012)

- acute renal failure (Haemolytic uraemic syndrome): 0.77 per 100,000 children pa
- steroid sensitive nephrotic syndrome 2-4/100,000 children pa
- antenatal hydronephrosis 1/100 live births

Prevalence

- Chronic kidney disease (dialysis and transplant): 59.3 per million age related population (pmarp) <16yrs* (reference 14th UK Renal Registry report July 2012).
- Chronic kidney disease (pre-end stage renal failure) approx. 53 pmarp. This is probably an underestimate. (Formal UK registry not available at present.)
- Steroid sensitive nephrotic syndrome 16/100,000 children

Renal transplantation

Approximately 130 per annum (pa) in the UK

Specialist expertise and support from multidisciplinary teams is required to lead the management of these conditions.

*Data provided for < 16yrs for prevalence and incidence of chronic kidney disease as registry data for 16-18yr olds currently incomplete due to some 16-18yr olds being managed in adult centres. This will be addressed in due course when the adult and paediatric data sets are merged, enabling more accurate data on this patient group.

Evidence of Standards of Care

Available from the Department of Health - www.dh.gov.uk

- Department of Health(2004) The National Service Framework for Renal Services, Services Part 1
- The National Service Framework for Renal Services, Part 2
- The National Service Framework for Renal Services: Working for Children and Young People
- Department of Health (2008) Commissioning Safe and Sustainable Specialised Paediatric Services

Available from the Renal Association - www.renal.org:

- Renal Association (2009-2012) The fifth edition of the Renal Association Clinical Practice
- Guidelines (on-line only)

Available from the British Association for Paediatric Nephrology - www.bapn.org:

- BAPN (2007) Haemodialysis clinical practice guidelines for children and adolescents
- BAPN (2007) Peritoneal dialysis clinical practice guidelines for children and adolescents
- BAPN (2010) Helping adolescents and young adults with established renal failure
- BAPN (2010) - standards for renal biopsy
- BAPN – standards for hypertension post-transplant
- BAPN (2011) Growth monitoring in children with chronic renal failure

- BAPN (2011) Improving the standard of care of children with kidney disease through Paediatric Nephrology networks.

Available in hard copy from BAPN - jane.tizard@uhbristol.nhs.uk

- BAPN (2003) Review of multi-professional paediatric nephrology services in the UK - towards standards and equity of care
- National Institute for Health and Care Excellence (NICE) - CG114 Anaemia management in people with chronic kidney disease: February 2011
- NICE- CG 54 Urinary tract infection: diagnosis, treatment and long-term management of urinary tract infection in children

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

2.1 Aims and objectives of service

The aim of the service is to improve both life expectancy and quality of life for children with renal disease by providing optimal specialised care and specifically:

- to identify children at risk of renal disease
- to prevent progression of disease where possible
- to provide appropriate care to those with established renal disease including support from full multidisciplinary teams to ensure support for the physical, psychosocial and emotional needs of the patient and their family
- to prevent complications of renal disease to provide equity of access to care
- to provide care as close to home as possible
- to ensure smooth and managed transition to adult services
- to support parents and families of children with renal disease as well as the affected child
- to ensure effective communication between patients, families and service providers

2.2 Service description/care pathway

The specialised service will provide the lead for nephrology services across the region. It will provide both inpatient and outpatient care for those with complex renal disease including those requiring dialysis (both acute and chronic) and will provide the support of the multidisciplinary team.

This specification will include the following:

- care within a specialist paediatric renal unit (both inpatient and outpatient) expert advice from a paediatric nephrologist 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 hospital
- expert advice from a paediatric nephrologist to the local hospital's general paediatrician caring for the child or, less commonly, to the GP, by letter, telephone, email or videoconferencing
- expert advice from non-medical multidisciplinary renal team members to other healthcare providers e.g. specialist paediatric renal nurses, dieticians, psychologists, pharmacists etc by letter, telephone, email or videoconferencing
- 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.
- specialist antenatal counselling
- transition pathways of care to adult services

Dialysis performed in a patient's home

Providers must directly reimburse households for additional direct utility costs associated with haemodialysis or peritoneal dialysis (this may include electricity, water, gas and telephone costs) received in the home. Criteria for receiving reimbursement are set out in the NHS England Service Specification [A06/S/b Haemodialysis to treat established renal failure performed in a patients home](#) and are applicable to households where children and young people receiving haemodialysis or peritoneal dialysis. Reimbursement should be provided to households meeting these criteria in line with the Trust reimbursement policy for adults receiving dialysis.

Clinical conditions that are managed by the specialist centre are described in Appendix 1 Groups A & B.

Interventions provided within/by a specialist renal centre include:

- hospital dialysis (i.e. haemodialysis(HD) and peritoneal dialysis) for acute kidney injury and chronic kidney disease
- training for home peritoneal dialysis and for home HD for chronic kidney disease
- access surgery for dialysis
- paediatric urology surgery
- plasmapheresis and immunoabsorption
- renal transplantation (for the two non-transplanting tertiary centres this will exclude the renal transplant admission and some of the early post-operative outpatient care which will be shared between the transplanting centre and the referring tertiary centre)
- renal biopsy
- urodynamics
- specialist paediatric and interventional radiology
- ambulatory blood pressure monitoring
- visits from members of the multi-disciplinary team to the patient's home to provide training and support to the child and the family/carers.

The service is commissioned to provide care for children as close to home as possible with the local hospital providing as much of the care as possible. This is

achieved by creating clinical networks, with each local hospital within the clinical network having at least one general paediatrician taking responsibility for children with renal disease, and the specialist renal centre providing support to the hospital clinician where appropriate. This will include the provision of outreach clinics in the district hospital led by the tertiary paediatric nephrologist. Each district hospital would be required to work within the network and comply with agreed standards with appropriately qualified clinicians. The place of care will depend on the clinical need and patient choice.

Patients must have equitable access to all treatment options which may entail travel to another tertiary centre for highly specialised treatment (for example combined liver kidney transplant, with liver transplantation already nationally commissioned). This means that some patients may travel significant distances for specialist care.

Infrastructure of specialist renal unit

The renal unit will require identified facilities for inpatient and outpatient care. Providing chronic haemodialysis (HD) requires an identified area for haemodialysis stations with HD machines, appropriate water supply and reverse osmosis suitable for dialysis. For acute HD, facilities need to be provided on the ward. Providing acute and chronic peritoneal dialysis requires space to be able to set up dialysis and to train parents/carers. Specific equipment for plasmapheresis and similar procedures is required which may be based on the renal unit or may be provided by an external source. For all surgical procedures appropriate theatre access is required with support services as detailed in section 2.5. Portable ultrasound is required for renal biopsy and ambulatory blood pressure (BP) machines are required for ambulatory BP monitoring.

The multi-disciplinary team essential to running a paediatric nephrology service will include:

- medical staff with trained paediatric nephrologists and junior staff in training, surgical expertise and other clinicians as detailed in section 2.5
- nurses (including those with special expertise in all forms of dialysis and transplantation)
- dieticians with expertise in renal disease
- pharmacists with both expertise in drugs used for treatment in renal disease and also the impact of renal failure on medication use.
- social workers
- psychologists
- play specialists/youth workers,
- teachers.

Services will be provided: 24 hours / seven days a week for referral of new patients and acute referrals of chronic patients:

- access to dialysis 7 days a week.
- day case: during week days
- outpatient clinics: during week days
- outpatient haemodialysis 6 days a week

- telephone advice to network providers available 24 hours/7 days a week
- telephone advice to carers available 24 hours/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

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.

Specifically, this service is for children up to the day before their 19th birthday with nephrological conditions or requiring procedures/interventions identified in the scope. However, patients will usually be transferred to adult services prior to their 18th birthday.

2.4 Any acceptance and exclusion criteria

The service will accept referrals from secondary paediatric services (including A + E services) and other tertiary paediatric services.

Some examples referral criteria include:

- chronic kidney disease (CKD) – all children with eGFR <90 will be referred to Special Paediatric Interest in Nephrology (SPIN)/Paediatric nephrologist.
- acute kidney injury (AKI) – all children with AKI that persists for > 24 hrs with deterioration in renal function will be discussed with a paediatric nephrologist and transfer arranged if appropriate.
- nephrotic syndrome (NS) - all children with NS will be referred to a paediatrician/ SPIN. All children with steroid resistant NS will be referred to a paediatric nephrologist.

In addition, direct referral of complex patients may occur from primary care within agreed protocols.

There will be agreed protocols for referral between secondary and tertiary care within the clinical network. Discharges will be proactively managed according to shared care arrangements.

There will be timely and appropriate communications with services that are expected to provide other parts of the patient's pathway in compliance with national guidance.

The following transition pathways will be in place to ensure safe transfer to adult services.

- Children with chronic kidney disease will remain under overall care of the paediatric nephrologist until transfer to the adult service.
- Children with acute kidney injury may be transferred back to the local paediatrician for routine surveillance once it is clear that the kidney disease has completely resolved. They may be re-referred if problems arise at a later time.
- Children with complex general nephrology problems are likely to remain under the overall care of the paediatric nephrologist but with shared care with the local paediatrician until transfer to the adult services. In some patients complete resolution of the condition may occur and the patient would be discharged from specialist services.

2.5 Interdependencies with other services

Acute kidney injury may be secondary to multi-system failure; hence there is need for close working between the specialist renal team and critical care services as well as other specialised paediatric (and occasionally adult) services. Emergency admissions of children with acute or chronic kidney disease may need immediate access to the following paediatric specialties:

- Paediatric specialised surgery, paediatric intensive care, paediatric anaesthesia, transplant and surgery for the transplanting units and urology. There is also a need for very close liaison with cardiology, neurology, haematology, immunology, respiratory, endocrinology, gastroenterology (including hepatology), ear nose and throat (ENT), neonatology, orthopaedics and rheumatology services.
- Commissioning Safe and Sustainable Specialised Paediatric Services - A Framework of Critical Interdependencies' sets out the relationships between the Paediatric nephrology service and other paediatric services in terms of the proximity or essential co-location of specific services necessary to provide a safe service. Essential support services include paediatric radiology and specialist renal histopathology. In addition, support from the full multidisciplinary team including nurses (including those with special expertise in all forms of dialysis and transplantation), dieticians, pharmacists, social workers, psychologists, play specialists/youth workers, teachers is essential. For transplantation, in addition to the surgical support, other support from the tissue typing service and transplant co-ordinators is required.
- Many nephrological conditions are managed by shared care arrangements between the specialist renal centre and the local hospital. Ongoing advice and support will be provided by the specialist centre to the local hospital as well as the provision of outreach clinics. Mild to moderate chronic kidney disease may be managed jointly between the specialist centre and the local hospital. However, all children needing inpatient dialysis and management of complex conditions require admission to the specialist renal centre. There is a close relationship between nephrology and urology services with joint care in many cases, particularly for patients with antenatally diagnosed problems. In addition

there are also combined clinics run with various other specialities e.g. with endocrinology, immunology rheumatology, genetics as well as transition clinics conducted jointly with adult nephrologists.

3. Applicable Service Standards

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

As in section 1 plus:

- All units will report standard data to the national renal dataset <http://www.ic.nhs.uk/services/datasets/dataset-list/renal>

Information Technology

Facilities to share clinical information as this is essential to the functioning of any network and for patient safety at all points along the care pathway.

Monitoring of children with renal disease is highly reliant on regular surveillance of biochemical parameters and key clinical information such as weight and blood pressure. It is essential that the results of the investigations and monitoring are readily available at all points of the network as clinical management plans often need to be made on the basis of these. Sometimes these need to be made on an urgent (same day) basis so rapid transfer of information is important.

There is a mandatory requirement for all adult and tertiary paediatric renal units to submit data comprising the national renal data set to the UK Renal Registry on all patients on renal replacement therapy. A renal IT system or equivalent that is capable of transferring the appropriate data is essential across the network. Access to the electronic renal record should be available in the local hospital setting so that data collected outside the tertiary centres can be included. This will facilitate monitoring of the outcomes of clinical care across the network and once established the system could be used to monitor and provide care for all children with kidney disease.

The provision of a renal IT system also allows patients and their families' access to Renal Patient View. This enables patients and families electronic access to their blood test results, medication lists, clinical letters and information about renal Conditions.

4. Key Service Outcomes

General outcomes

- To minimise mortality and morbidity by providing the most appropriate care for children with renal disease
- To ensure that there is a sufficient, skilled and competent multi-disciplinary workforce to manage children with renal disease
- To ensure that children are treated as close to home as possible through a

commissioned clinical network of care

- To ensure that children have their healthcare and any social care plans coordinated
- To ensure children with renal disease are treated in line with national guidelines and agreed local pathways

To ensure equity of access to care for all aspects of renal disease

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 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 March2010). 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 continuous 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.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) training (2) and should maintain the competencies so acquired (3)*. 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 screening (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

- Guidance for Providing Anaesthetic Services (GPAS) Paediatric anaesthetic services. Royal College of Anaesthetists (RCoA) 2010 (www.rcoa.ac.uk)
- Certificate for Completion in 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 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 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 persons 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 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 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 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 whilst respecting their human rights and confidentiality, and ensuring 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 about 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 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 making appropriate arrangements for the obtaining, recording, handling, using, safekeeping, 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, as well as 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

A) Conditions managed by a specialist renal centre include:

- acute kidney injury including those requiring haemodialysis (HD) or peritoneal dialysis (PD)
- moderate and severe chronic kidney disease (i.e. chronic kidney disease KDOQI categories 3-5 including those on chronic dialysis HD or PD).
- complicated nephrotic syndrome
- severe or chronic/complex glomerular disorders
- vasculitis (except mild Henoch-Schonlein purpura)
- tubulointerstitial disorders including renal tubular transport disorders that are primary or secondary to acquired or metabolic disease
- complex/severe hypertension
- nephrolithiasis
- complex neuropathic bladder particularly those requiring other specialised services.

All rare diseases currently commissioned through the Highly Specialised Services

Specification will be included in the scope.

B) Conditions that may be managed in secondary care and, where more complex, under a shared care arrangement with the specialist renal centre include:

- uncomplicated urinary tract infection nocturnal enuresis
- daytime enuresis
- antenatal hydronephrosis/malformations
- chronic kidney disease (mild-moderate CKD 1-2)
- acute kidney injury not requiring dialysis (if mild and uncomplicated)
- uncomplicated nephrotic/nephritic syndrome
- haematuria proteinuria
- mild/moderate hypertension.

Change form for published Specifications and Products developed by Clinical Reference Group (CRGs)

Product name: Paediatric Medicine: Renal

Publication number: E03/S/a

Description of changes required

Describe what was stated in original document	Describe new text in the document	Section/Paragraph to which changes apply	Describe why document change required	Changes made by	Date change made
N/A	<p>Dialysis performed in a patient's home</p> <p>Providers must directly reimburse households for additional direct utility costs associated with haemodialysis or peritoneal dialysis (this may include electricity, water, gas and telephone costs). Criteria for receiving reimbursement are set out in the NHS England Service Specification A06/S/b Haemodialysis to treat established renal failure performed in a patients home and are applicable to households where</p>	Page 4.	To promote equity in access to reimbursement arrangements and clarify that children and young people should receive reimbursement in line with the Trust's reimbursement policy for adults receiving haemodialysis in their home.	Paediatric Medicine CRG Lead Commissioner.	June 2022.

	children and young people receiving haemodialysis or peritoneal dialysis. Reimbursement should be provided to households meeting these criteria in line with the Trust reimbursement policy for adults receiving dialysis.				
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