

SCHEDULE 2 – THE SERVICES

A. Service Specifications

Service Specification No.	A06/S/a
Service	In centre haemodialysis (ICHD): main and satellite units
Commissioner Lead	
Provider Lead	<i>The name of the individual leading on the service for the provider</i>
Period	<i>12 months</i>
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

End stage renal failure (ESRF), also known as established renal failure (ERF), is an irreversible, long-term condition as a result of chronic kidney disease for which regular dialysis treatment or transplantation is required if the individual is to survive. If the kidneys fail, the body is unable to excrete certain waste products, excess water, acid and salts resulting in increasing symptoms and eventually death. When ESRF is reached, renal replacement therapy (RRT), in the form of dialysis or transplantation, is required as a life-saving and life-sustaining measure. In 2011, 108 patients per million (ppm) population in the UK started renal replacement therapy (RRT) for established renal failure but the UK Renal Registry showed significant variation in the crude acceptance rate from 50 to 226 ppm. Some of this variation is explained by ethnicity and socioeconomic deprivation both of which influence the prevalence of kidney disease.

This specification focuses on haemodialysis which takes place in main or satellite dialysis units (adults) and forms just one part of a wider portfolio of detailed specifications for RRT. In recent years there has been a growing recognition that, in patients who are not transplanted, self-care in the home or in a community centre by either peritoneal or haemodialysis should be encouraged wherever possible to enhance health and quality of life prospects. Where these treatments are inappropriate or difficult to establish and whenever patients choose it, in-centre

haemodialysis (ICHD) is the mainstay of treatment. . The prevalence rate for patients receiving ICHD was 365 pmp in England in 2011. In England in 2011 82.2% of patient being treated with chronic dialysis received that as ICHD.

All 52 renal referral centres in England have an integral haemodialysis unit. These are referred to as Main Renal Units (MRUs). In addition to providing an essential support function for in-patient renal care including new and unstable patients they typically also provide routine ICHD for patients who live near to the main hospital. In 2011, 43% of ICHD patients in England were treated in MRUs.

In 2011 57% ICHD patients in England were treated in satellite units. At the time of writing 46 of the 52 renal referral centres have 'satellites' around them, some over five, the majority less than 3. Satellite renal units may be located in district general hospitals, or in other healthcare facilities (eg GP practice). Others are 'freestanding', often in industrial locations in towns and cities. Those in hospitals have the advantages of convenient access to other healthcare services and investigations, the latter having the advantage of 'locality', easy access and parking. Some years ago it was shown that there was little difference in the case-mix of patients managed in satellites or MRUs (Roderick et al). This is reflected in uniformity of tariff for ICHD patients, irrespective of dialysis location.

While the majority of ICHD units are managed by the NHS a number are managed by the independent sector. This includes a small number of MRUs. Over 30% of patients are thought to be treated by the independent sector, mainly in satellite units, and this proportion has increased year on year. While independent sector provider typically provides the building and equipment and employs the nursing staff other models exists in which the independent provider provides the non-clinical aspects of the service and the nurses remain in the NHS, accountable to the senior NHS nurse manager in the MRU. In all cases hitherto, the doctor who assumes the responsibility of continuity of care of the patient, remains an NHS employee of the Trust of the MRU. Similarly, access to other members of the multi-professional renal team most often are directly employed by the local NHS MRU but not exclusively so.

ICHD is a specialised service commissioned by NHS England, but there are currently different models whereby satellite ICHD, be it NHS or independent sector, is commissioned either directly from the centre or it is subcontracted from the local MRU which receives the tariff payment.

Haemodialysis patients are dependent on the maintenance of 'vascular access' to allow repeated connection to the HD machine. The need to maintain a satisfactory vascular access coupled with a high susceptibility to cardiovascular disease, dialysis patients present some of the most serious challenges encountered by vascular surgeons and interventional radiologists. A significant proportion of these interventions are required to be delivered urgently or as an emergency. The safety of dialysis patients while hospitalised with vascular complications of their disease requires special consideration in the commissioning of dialysis services.

1.2. Evidence Base

The National Service Framework (NSF) for Renal Services (Department of Health, 2004/5)

NHS Estates Health Building Notes 07-01 Satellite Dialysis Unit and 07-02 Main Renal Unit. 2009

European Best Practice Guidelines Expert Group on Haemodialysis. Nephrology Dial Transplant 2007; 22: (Suppl 2) S1–S120.

Clinical Practice Guidelines for Haemodialysis: UK Renal Association, 5th Edition, April 2010

Roderick P et al: An evaluation of the costs, effectiveness and quality of RRT provision in renal satellite units in England and Wales. Health Technol. Assess 2005; 9(24)

The Renal Team: A multi-professional renal workforce plan for adults and children with Renal Disease. Recommendations of the National Workforce Planning Group. British Renal Society: 2002

UK Renal Registry. Nephron. Clin. Prac. Vol. 120, Suppl. 1, 2012. 14th Annual Report of the Renal Association.

A Home Dialysis Manifesto. Findings of the 2013 Home Dialysis Summit. National Kidney Federation (NKF). Ed control: All-Party Parliamentary Kidney Group.

Nice Guidance CG73: Chronic kidney disease (2008)

Nice Guidance CG114: Anaemia management in people with chronic kidney disease (2011).

End of Life Care in Advanced Kidney Disease: A framework for implementation. NHS Kidney Care, National End of Life Care Programme, 2011.

2. Outcomes

2.1 NHS Outcomes Framework Domains & Indicators

Domain 1	Preventing people from dying prematurely	√
Domain 2	Enhancing quality of life for people with long-	√

	term conditions	
Domain 3	Helping people to recover from episodes of ill-health or following injury	√
Domain 4	Ensuring people have a positive experience of care	√
Domain 5	Treating and caring for people in safe environment and protecting them from avoidable harm	√

Patient Reported Outcome and Experience Measures should be prioritised and should be the principal barometer of. Improved quality of life and experience for both patients and carers should be sought.

The ICHD service aims to deliver the following outcomes:

- Patient centred and integrated care (domain 4)
- Improved patient life expectancy and the prevention of avoidable death from kidney disease or its complications (domain 1)
- Improved clinical outcomes (domain3)
- Improved quality of life and experience of care for people with end stage kidney disease and their family/carers (domain 2)
- Provision of care in a harm-free environment (domain 5)
- Provision of cost-effective services
- Care delivered at the appropriate time and place.(domain 3)
- Equity of service provision (domain 4)
- Innovation in service delivery

To provide a safe, cost effective, high quality specialist service for people with end stage kidney disease treated with ICHD to improve both life expectancy and quality of life by (domain 2, 5):

- Providing a personal service, sensitive to the physical, psychological and emotional needs of the patients and their families/carers
- Ensuring equity of access to services for those with kidney disease taking into account a patient's choice of RRT modality, location and the distance they travel
- Ensuring the opportunity for patients to share (contribute) to their care by education to enable them to participate in the tasks relating to haemodialysis treatments
- Facilitating autonomy and transition to adult care by additional support. Such support is to be patient centred and enabling patient choice. Consideration will be given to the particular educational and employment needs of these patients.
- Facilitating transition to conservative and end of life kidney care
- Ensuring effective communication and support between patients, families/carers and the service providers

National Renal Dataset

The provider will ensure that the required patient, activity and outcomes data is

provided in accordance with the requirements of the National Renal Dataset. The National Renal Dataset has been approved as a Full Operational Information Standard by the Information Standards Board for Health and Social Care. The dataset is mandated for collection by the Department of Health, <http://www.ic.nhs.uk/services/datasets/dataset-list/renal>

Renal Registry

The provider will ensure that the required patient, activity and outcomes data is provided in accordance with the requirements of the UK Renal Registry: <http://www.renalreg.com/>

Renal Patient View System

The provider will ensure that patient health records and any other personal data relating to a patient's treatment are returned to the national Renal Patient View System for those patients who wish to participate in this system.

3. Scope

3.1 Aims and objectives of service

Key objectives of renal replacement therapy (RRT) are to extend life quality and expectancy for those with advanced kidney failure who are likely to benefit.

Services will be patient-centred, and offer safe, effective, evidence-based therapies in appropriate care settings.

Patients will be supported to make informed choices regarding their treatment options and in managing their condition to achieve their goals and their best possible quality of life.

3.2 Service description/care pathway

The provider will deliver ICHD Services that:

Infrastructure:

Are provided in a safe and secure environment in a facility which complies with NHS Estates Building Notes and which meets all the technical standards detailed in the Renal Association Guidelines.

Access to entertainment including free to air television should be provided, internet access is desirable.

That the design of the centre meets the requirement to isolate patients using a dedicated dialysis machine when returning from dialysing in areas with high risk of blood borne virus transmission.

The provider will ensure that all equipment used in the delivery and monitoring of haemodialysis is CE marked and approved to ensure compliance with the relevant safety standards BS EN 60601-1:2006 'General safety standards for electrical equipment in clinical use' 2010) and BS EN 60601-2-16:2008 'Particular requirements for basic safety and essential performance of haemodialysis, haemodiafiltration and haemofiltration equipment' and Renal Association guidelines (2009).

Water treatment standards must comply with all Renal Association guidelines.

Providers will offer Renal Patient View (RPV) to every patient treated in MRUs and Satellite haemodialysis units. Patients will be encouraged to advise their GP if they register with RPV.

Providers should have in place electronic download of all information required by the UK Renal Registry. The provider must ensure 100% of the data-set required is communicated to the UKRR including individual primary diagnosis and co-morbidity profile.

In the event that the provider is unable to provide sufficient equipment for treating patients at any time, or in the event of technical difficulties, or other emergencies, the provider shall have contingency systems in place. These should include the ability to provide or procure alternative dialysis sessions at other facilities.

Clinical Management:

Provide a specific support for those patients who start dialysis as late presenters or unplanned from within the kidney service to ensure that they receive appropriate information. These patients should be offered the same range of choices regarding their RRT modality.

Providers must offer education about access to self care training for patients interested in contributing to their management by participating in the tasks relating to haemodialysis treatment. In particular, this should include the opportunities for health gain offered by self-care either in the dialysis facility itself or by carrying out more frequent haemodialysis/peritoneal dialysis treatment in the home.

Ensure clear arrangements are in place for continuity of care which requires identifying the nephrologist responsible for each patient's management. There are arrangements whereby all patients have access to a multi-professional renal team for regular review and for also for ad-hoc input into their care.

In some patients who have retained some of their natural renal function, twice weekly sessions may be possible for a period. Similarly less frequent dialysis is sometimes prescribed as part of a package of palliative care. These variations are determined by the nephrologist and they should be fully discussed with the patient and their carer and the reasons clearly recorded in the patient's record.

A number of haemodialysis patients cannot maintain adequate fluid and blood pressure control on the normal dialysis prescription of thrice weekly sessions, often because of co-existing cardiac dysfunction. Higher frequency haemodialysis can control this condition. Patients in whom a greater frequency of treatment than three times a week is clinically indicated would normally be considering home haemodialysis.

For those patients where this is impractical the provider must be able to accommodate requests from consultants for frequent haemodialysis in either an MRU or satellite facility.

The provider shall ensure that it adheres to all national policies and guidelines relating to infection control and decontamination. The provider will take all steps required to reduce the risk of the spread of any infections to patients. This will include the provision of information to patients and carers regarding infection control processes.

The provider will have in place a protocol for ensuring vaccination against hepatitis B virus, delivered in primary care.

The provider will ensure that all patients in MRUs, and satellite units, should be included in the clinical governance (CG) processes of the MRU. By embedding CG within day to day operations there should be a commitment to monitoring clinical quality and outcomes. Delivery of care must be safe, timely, effective, efficient, equitable, patient centred and sustainable.

As ICHD is only one component in the continuum of the renal patient pathway. The monthly MDT review should review the on-going suitability of this dialysis modality. This is the appropriate place to update care plans. In particular, the opportunities for health gain offered by self-care either in the dialysis facility itself or by carrying out more frequent haemodialysis/peritoneal dialysis treatment in the home.

The Monthly MDT review will review suitability for transplant listing for all patients not on the transplant list and the suitability for patients so listed to remain on the waiting list.

Staffing structure:

The provider will ensure that the haemodialysis station-capacity and staffing is sufficient to enable patients to access haemodialysis as frequently as clinically prescribed and with sufficient flexibility of timings to allow patients minimal interruption to their work and family commitments.

The provider will ensure that the nurse staffing levels in haemodialysis units are adequate to manage the delivery of care. That the level of nurse staffing in all renal units is adjusted for the dependency of the patient group and in main renal units has capacity to treat with haemodialysis those patients (who usually dialysis in satellite units) during periods of in-patient care.

Providers of ICHD should have clear referral pathways for vascular surgery and interventional radiology in order to establish new fistulae and for fistula salvage and maintenance. Where tunnelled venous catheters (TVCs) are the only option (or the patient's choice) then providers must have strategies and protocols in place to minimise the risk and manage the complications of this type of vascular access, including infection and traumatic damage of blood vessels. These pathways should include pathways for urgent interventions.

In patient care for ICHD patients

Providers shall ensure that haemodialysis patients are managed in a safe environment when hospitalised. There should be 24/7 and urgent on-site cover available from

vascular surgeons, interventional radiologists, nephrologists and acute dialysis team. Patients should not be transported to another hospital for their regular maintenance dialysis or for 'acute' dialysis during a period of hospitalisation unless under exceptional circumstances, such as admission is for another treatment by another specialised service that is not co-located within a hospital with a renal unit.

The provider will ensure that clear protocols are in place for the urgent transfer of patients for in-patient care in the event of intercurrent medical emergencies. In the case of satellite units these include 'blue-light' transfer to the nearest A&E department, or urgent transfer to the MRU. Receiving departments must be fully appraised of and in agreement with the protocols.

Adolescent transition

Specialist support, that is patient centred and enables patient choice, will be provided for young adults (age 18-25). This will include those who are in the process of transferring from paediatrics, those who have transferred from paediatrics or those who have come straight into adult services at a young age. Transition will involve a period of joint care from paediatric and adult services and it is important for multi-disciplinary teams (MDTs) to be aware that this group may have additional developmental needs, including educational and employment.

Withdrawal of dialysis treatment

For those patients who wish to withdraw from treatment the provider will ensure that they will receive coordinated support and care in accordance with the best principles of end-of-life management.

The Multi-Professional Renal Team

End stage renal failure is often a devastating life changing event which impacts on physical and mental health, employment and on relationships. Care of the dialysis patient entails far more than simply the execution of the dialytic process by specialised haemodialysis nursing staff. The following inputs are required.

Nutrition and dietetic services

The provider will provide access to a dietetic service for patients. Patients will be seen by the dietician as required. In addition, patients will have access to telephone advice and literature as clinically required.

The provider will ensure services are in situ which allow an average provision for renal dietetic assessment on a quarterly basis in patients with unstable diet related electrolytes, or a consistent trend in flesh weight change. The frequency of monitoring may need to increase to monthly in a proportion of patients who have a very poor appetite and a significant weight loss. Those stable on dialysis (stable weight and stable diet related electrolytes) may only need 6 monthly reviews. The prioritisation and frequency of review to be decided by the patient's renal dietician.

Providers will supply patients during a ICHD session with a drink and an appropriate snack directed by dietetic advice.

Pharmacy services

The provider will ensure that medications required during ICHD are prescribed and dispensed. This will include intra-venous fluids and medications as well as anticoagulants.

The provider will prescribe and dispense erythrocyte stimulating agents (ESAs) and cinacalcet.

Pharmacy advice, support and stock drugs will be provided via an agreement between providers if appropriate.

Medicines management

The provider is expected to have in place a medicines management procedure.

The provider shall comply with the higher standards of (i) National Minimum Standards and (ii) the highest available Clinical Negligence Scheme for Trusts (CNST) Standard in relation to medicines management as updated from time to time. Patients should receive a regular scheduled formal medicines management review and this should be done routinely whenever a patient changes clinical locations for their care.

In line with national guidance, intravenous iron will be delivered in an environment with access to medical equipment that is able to deal with potential side effects and proportionate to the risk of such side effects.

Social work support

The provider will offer patients access to social work advice as required.

Patients receiving dialysis have complex medical, emotional and social needs. Access to a broad range of professionals is essential for delivering renal replacement dialysis therapy. The provider shall have sufficient clinical and support staff to ensure a multi-disciplinary approach to provision of services in respect of, and at all times in accordance with, good clinical practice.

Psychology services

The provider will offer patients access to psychology services as required. Applied psychologists include clinical psychologists, counselling psychologists and health psychologists. Psychologists offer evidence based psychological assessment and intervention for patients, their carers and families as well as clinical supervision for direct care staff, training on aspects of psychological care, input to service development and clinical governance and consultation as well as conducting research, audit and service evaluations

Recommended staffing levels for the above groups (Nursing, Dietetics, Pharmacy, Social Work, Psychology) have been declared by The British Renal Society

Patient Support Groups

The provider will ensure that patients and carers are provided with information about local and national support groups and how to access them, including such groups' involvement in patient education sessions organised by the provider as it is recognised that these are a vital source of peer support, advice and information for patients. Signposting information will be displayed within the provider's facilities.

Transport, Travel and Waiting Times

The provider should have robust and responsive relationships with the Patient Transport Service, ambulance service and local taxi firms.

The provider will ensure in conjunction with the transport provider compliance with Renal Association recommendations on patient travel time subject to geographical location. The provider should seek to provide haemodialysis services as close to the patients' home as possible.

After arrival at the unit the time of treatment initiation should be within the timeframe of that recommended in the Renal Association guidelines.

Self-transporting ICHD patients **should not be charged** for parking and any such charges will be reimbursed to the patient.

Dialysis Away From Base (DAFB)

The provider will facilitate arrangements for patients who wish to, or need to travel on a temporary basis, to other parts of the UK and those wishing to travel outside the UK in accordance with national agreements on the management of dialysis away from base. **National policy is currently being developed.**

Training to become self-supervised on mobile haemodialysis machines should be offered so that patients can travel freely in the UK, Europe and overseas.

End of Life Care: Withdrawal from Dialysis

For those patients who express a desire to withdraw from treatment, the provider must have clear protocols for the management of the situation which will involve liaison with a palliative care team experienced in the management of withdrawal.

Liaison with primary care services is also essential.

Withdrawal from dialysis may form part of an agreed palliative care treatment plan developed jointly between the clinician, the patient and their carers.

Information System (IT)

The provider will utilise information systems which both meet the requirement to submit data to the UK Renal Registry of the Renal Association and UK Transplant (UKT) for comparative audit purposes, and the additional information requirements outlined in the Renal National Service Framework and any other local requirements set out by the commissioner of the service. Clinical audit information should be made available to patients in an accessible format.

Where the provider operates multiple units, they will ensure that the same information system is installed with real time data transfer. Failing this, the provider will ensure that the systems employed interface with the provider's main clinical and management systems (including PAS), seamlessly, fully and without delay. The provider's renal information system for best should access to patient letters, discharge summaries and details of inter-current events taking place.

The electronic record in the renal information systems may include:

- Records of individual haemodialysis treatment including treatment time and clinical observations (blood pressure, temperature etc.);
- Haemodialysis orders;
- Drug prescriptions;
- Pathology results;
- Major events; and
- Record of nursing care;
- Renal Patient View.

3.3 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

3.4 Any acceptance and exclusion criteria and thresholds

ICHD should be offered to any patient reaching or presenting with established renal failure if it is deemed by the clinician in charge that the patient will benefit from treatment.

This specification refers to adults over the age of 18 years. Some young people aged less than 18 years may be best treated in an adult service, by mutual consent.

Satellite units, whether NHS or independent sector should have the same acceptance criteria as the MRU. Exclusions should not be on the basis of age (advancing age or adolescence), co-morbidity, frailty or type of vascular access.

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)

3.5 Interdependencies with other services/providers

Medical cover for emergencies

Pathology

Surgical and Intervention radiology procedures

Acute Admissions Wards

Accident and Emergency

Intensive Care

Psycho-social support

Pharmacy services

Vascular access

Nutrition and dietetic services

Anaemia management

Hepatitis B vaccination

Social care & work advice, including that relating to benefits

Related Services

General Practitioners and community services

General Practitioners with Special Interests

Secondary provider clinicians and specialist nurses

Specialist transplant providers

Patient transport services

Medical Physics renal technical teams

NHS estates staff

Environmental waste service

Many people with CKD also have other medical conditions, particularly diabetes, depression and cardiac conditions. It is therefore essential that strong clinical linkages are made with other services, preferably with care provided from a multi-disciplinary team setting.

4. Applicable Service Standards

4.1 Applicable national standards e.g. NICE

The provider is expected to comply with the legislative provisions of renal replacement therapy and the Care Standards Act (2000), and to provide services in accordance with regulations as defined by, but not limited to, the following authorities and organisations which may change over time:

3.1 Regulatory bodies and legislation

Care Quality Commission and any successor organisations; and

All applicable law on Health and Safety at work

Anti-discrimination and equal opportunities legislation

General Medical Council

3.2 Professional bodies with an interest and national guidance

Renal Association Clinical Practice Guideline for Haemodialysis 2010

UK Renal Registry

British Renal Society

British Transplantation Society including all relevant clinical practice guidelines

National and local health service bodies and relevant local government authorities

Strategic Clinical Networks

NICE guideline Anaemia management in people with chronic kidney disease 2011.

NHS Employment Check Standards

CNST General Clinical Risk management standard appropriate to the service being delivered;

National Service Framework for Renal Services

Royal College of Physicians Clinical Standards for Renal Services

4.2 Applicable standards set out in Guidance and/or issued by a competent body (e.g. Royal Colleges)

5. Applicable quality requirements and CQUIN goals

5.1 Applicable quality requirements (See Schedule 4 Parts A-D)

5.2 Applicable CQUIN goals (See Schedule 4 Part E)

6. Location of Provider Premises

The Provider's Premises are located at:

Appendix 1

Quality standards specific to the service using the following template

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
Domain 1: Preventing people dying prematurely			
To reduce the incidence of MRSA and MSSA bacteraemia related to vascular access	No more than one bacteraemia per 25 patient years of receiving treatment	Number of bacteraemia per 100 patient years receiving treatment. Annual audit.	As per Standard NHS Contract General Conditions Clause 9 (GC9) Remedial Action Plan
Domain 2: Enhancing the quality of life of people with long-term conditions			
Monthly MDT review to assess on-going suitability of ICHD for the patients. To include a review of suitability for transplant listing. To increase the number of patients accessing	Benchmark followed by action plans for improvements if proportion of patients active on the transplant list/receiving home dialysis is in lower quartile of national performance	% of patients active on the transplant list as a % of all ICHD patients. Numbers of patients who change to home dialysis. Annual audit	As per Standard NHS Contract General Conditions Clause 9 (GC9) Remedial Action Plan

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
transplant and home dialysis.			
Domain 3: Helping people to recover from episodes of ill-health or following injury			
To ensure patients are informed and involved in their care.	Benchmark followed by action plans for improvement.	<p>% of patients who are able to undertake a minimum of 5 tasks related to their haemodialysis treatment independently.</p> <p>Annual Audit.</p>	As per Standard NHS Contract General Conditions Clause 9 (GC9) Remedial Action Plan
Domain 4: Ensuring that people have a positive experience of care			
To ensure informed patient choice and to be involved in shared decision making	Benchmark to be followed by evidence of improvement.	<p>Annual Audit: Patients and carers survey on quality of service together with satisfaction with choice of RRT and patient reported health related quality of life.</p> <p>2. Number and % of patients with access and instruction in the use of Renal Patient View.</p>	As per Standard NHS Contract General Conditions Clause 9 (GC9) Remedial Action Plan

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
		3. Number and % of patients utilising shared decision making aids/actively involved in shared decision making.	
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm			
To increase the number of patients receiving ICHD with permanent access.	85%	% of patients with a fistula/graft of all haemodialysis patients. Annual audit.	As per Standard NHS Contract General Conditions Clause 9 (GC9) Remedial Action Plan

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 (DOH) & 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 – DOH

Imaging

- All services will be supported by a 3 tier imaging network ('Delivering quality imaging services for children' DOH 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 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.¹ All UK anaesthetists undergo training which provides them with the competencies to care for older babies and children with relatively straightforward surgical conditions and without major co-morbidity. However those working in specialist centres must have undergone additional (specialist) training² and should maintain the competencies so acquired³ *. These competencies include the care of very young/premature babies, the care of babies and children undergoing complex surgery and/or those with major/complex co-morbidity (including those already requiring intensive care support).
- As well as providing an essential co-dependent service for surgery, specialist anaesthesia and sedation services may be required to facilitate radiological procedures and interventions (for example MRI scans and percutaneous nephrostomy) and medical interventions (for example joint injection and intrathecal chemotherapy), and for assistance with vascular access in babies and children with complex needs such as intravenous feeding.
- Specialist acute pain services for babies and children are organised within existing departments of paediatric anaesthesia and include the provision of agreed (hospital wide) guidance for acute pain, the safe administration of complex analgesia regimes including epidural analgesia, and the daily input of specialist anaesthetists and acute pain nurses with expertise in paediatrics.

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

○ **References**

1. Guidelines on the Provision of Anaesthetic Services (GPAS) Paediatric anaesthetic services. Royal College of Anaesthetists (RCoA) 2010 www.rcoa.ac.uk
2. Certificate of Completion of Training (CCT) in Anaesthesia 2010
3. CPD matrix level 3

Specialised Child and Adolescent Mental Health Services (CAMHS)

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

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

- Facilities and environment – essential Quality Network for In-patient CAMHS (QNIC) standards should apply (<http://www.rcpsych.ac.uk/quality/quality,accreditationaudit/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 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 2RCNs 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.
- Participates in local safeguarding children boards where required and understand their responsibilities and the responsibilities of others in line with the Children Act 2004.
- Having clear procedures followed in practice, monitored and reviewed in place about the use of restraint and safeguarding.

- Taking into account relevant guidance set out in the Care Quality Commission's Schedule of Applicable Publications
- Ensuring that those working with children must wait for a full CRB disclosure before starting work.
- Training and supervising staff in safeguarding to ensure they can demonstrate the competences listed in Outcome 7E of the *Essential Standards of Quality and Safety*, 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)
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 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
 - ensuring 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