

#### **SCHEDULE 2 – THE SERVICES**

#### A. Service Specifications

| Service Specification No. | A06/S/b   |
|---------------------------|---|
| Service                   | Haemodialysis to treat established renal failure performed in a patients home |
| Commissioner Lead         |   |
| Provider Lead             |   |
| Period                    | 12 Months   |
| 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 or the person will die within weeks or months.

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 in England 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. The purpose of a RRT service is to offer people approaching end stage renal failure a choice of treatment modalities depending on their individual health and circumstances, delivered close to or in the home, providing education and support to achieve the best possible quality of life. Preparation and choice for this patient group are central principals that underpin the RRT service. The number of patients receiving home HD (in UK) increased by 19% from 905 patients in 2011 to 1080 patients in 2012.

There is good evidence that home dialysis therapies (both peritoneal and haemodialysis) offer advantages for suitable patients. The limitations of thrice weekly standard in-centre haemodialysis have been recognised in recent years, in particular, the increased risk of hospitalisation or death after the 'two-day break' (Foley R. N. Engl J Med 2011; 365). Although it is very difficult to separate the effect of different case mix the most up to date and comprehensive data does not show a survival difference between patients who received more frequent versus thrice weekly (standard regimen) haemodialysis (Kid Int 2011, 80(10): 1080-91) The advantage of self-care haemodialysis includes not only those related to control and convenience but also the opportunity to conduct more frequent or longer sessions to optimise health prospects. Improvements in the cardiovascular risk profile of patients on 'daily' treatment have been demonstrated (Frequent Haemodialysis Network, NEJM, Nov 2010). The introduction of smaller more portable haemodialysis machines also provides opportunity for travel for employment or holidays. Furthermore, these therapies are cost effective in the UK when compared with hospital treatments and have been demonstrated to be safe.

The National Institute of Health and Care Excellence (NICE) technology guideline No 48 (2002) stated that "making the assumption that 10 to 15% of dialysis patients, given the choice, would opt for home haemodialysis, expansion of the services to support home haemodialysis will be required". Approximately 4% of those patients treated by haemodialysis receive that treatment at home. This is equivalent to a prevalence rate of approximately 14 per million population in England.

In 2012 the percentage of dialysis patients receiving home haemodialysis in England varied from 0% in 5 centres, to greater than 5% in 17 centres in England with one centre achieving 11.5% (UK Renal Registry)

The principal should be that home haemodialysis should always be an option for patients and that solutions should be sought to overcoming barriers that might prevent this.

Decisions should be made on an individual basis but in general, patients suitable for home haemodialysis will be those who - (NICE Technology Appraisal guidance No 48, Sept 2002):

- have the ability and motivation to learn to carry out the process and the commitment to maintain treatment
- are stable on dialysis
- are free of complications and significant concomitant disease that would render home haemodialysis unsuitable or unsafe
- have good functioning vascular access
- have a carer who has (or carers who have) also made an informed decision to assist with the haemodialysis unless the individual is able to manage on his or her own
- have suitable space and facilities or an area that could be adapted within their home environment.

#### 2. Outcomes

#### 2.1 NHS Outcomes Framework Domains & Indicators

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

The following are expected outcomes of the home haemodialysis service:-

#### Patients (domains 2 & 4)

Patients are able to make an informed choice and shared decision making about treatment options, including home haemodialysis.

Education given to patients is evidence based and timely outlining benefits and disadvantages.

Patients currently accessing dialysis therapies are assessed and informed of treatment options annually.

Education and training programmes are against time frames and supported by competencies.

Evidence of flexible dialysis treatments – overnight etc.

Clear consistent national guidelines for the capital costs of home adaption, remote tele-monitoring and on- going funding for electricity, water and telephone costs due to dialysis treatment need to be put in place to ensure equity.

Patients and their carers are able to give formal annual feedback on the quality of the service Patient reported outcome and experience measures should be prioritised, and should be the principal barometer of success. Improved quality of life and experience for both patients and carers should be sought.

#### Specialist Renal Unit (domains 2 4 & 5)

An agreed eligibility criteria.

An educated workforce to support training for home haemodialysis (HHD) and self- care competencies.

A clinical champion to promote HHD and set targets for improvement.

Home therapies education and preparation to be appropriately timed; early discussions are essential as well as revisiting options.

A self-care area within main centre and/or satellite units.

An audit programme.

Technical support.

Home adaptation policy.

Electrical and water and telephone funding support.

An accelerated pathway option to accommodate non-planned starters.

Review of home therapies option with patients established on hospital or satellite centre haemodialysis during regular clinical reviews in outpatients or on the dialysis unit.

Capacity to accommodate home therapies.

Capacity for home visits and review of home circumstances.

High quality education to be delivered according to best practice.

Patient to have a named nurse/contact for queries.

Patients to have the opportunity to revisit education at regular intervals or have further education if necessary.

For all home therapies options relevant support services need to be involved at an early stage.

#### Culture (domains 2 3 4 &5)

A culture of shared-care for haemodialysis treatment.

A culture to provide home haemodialysis to all patients who choose this option when it is clinically appropriate, practical and cost-effective.

A culture of shared decision making is to be promoted

Home therapies are to be included in the training of all renal clinical professions

Create culture of environmental sustainability in kidney care – raising awareness amongst staff and patients.

#### 3. Scope

#### 3.1 Aims and objectives of service

The aims of this service are:

- to improve the wellbeing and quality of life for patients receiving renal replacement therapy.
- to provide home haemodialysis to all patients who choose this option when it is clinically appropriate, practical and cost-effective.

The objectives of this service are:

- to provide an emphasis on patients being involved in their own care as much as possible.
- to achieve equity in patient access to all treatment modalities acknowledging the limitations listed above.
- to seek solutions to overcoming barriers that might prevent treatment choice.
- to ensure that information and training for home haemodialysis are given in a timely manner.
- to make home dialysis services responsive to patient and carer's feedback.
- to maximise the value gained from NHS resources.
- to introduce new technologies and service innovations in a timely way including remote monitoring when supported by appropriate funding.
- to audit the quality of the service, including patient and carer feedback, on a regular basis.

#### 3.2 Service description/care pathway

The provider will manage referrals in line with any relevant national or local guidelines or recommendations, and in accordance with the agreed response times. All patients will be managed by a multi professional team. Shared decision making principals and access to tools will be part of the standard operating policy.

The model of a Consultant with a particular focus on a group of patients treated by home haemodialysis, who are reviewed both in an out-patient environment with access to in-patient care and monitoring via a multi-disciplinary team (MDT) will be common to all units. The number of staff required and the detail of the frequency of clinics and MDT meetings will be determined by the scale of each service.

The provider will either provide home haemodialysis services or will arrange onward referral to another unit that offers:

- Assessment of suitability for home haemodialysis including a risk assessment and decision by the MDT on a patients suitability to dialyse at home alone.
- Capacity to offer timely training for home haemodialysis
- Expertise and capacity to assess suitability of home for dialysis instillation.
- Capacity to carry out adaptations to patients home.

- Surgical and interventional radiology procedures related to the establishment and maintenance of dialysis including procedures for establishing new fistulae, fistula salvage and peritoneal access.
- MDT review typically at monthly intervals for stable patients
- As home haemodialysis is only one component in the continuum of the renal
  patient pathway, the monthly MDT review should review the on-going suitability of
  the dialysis modality. This is the appropriate place to update care plans. 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.
- Medical cover for emergencies.
- Ongoing assessment and support in the home by a member of the multidisciplinary team.
- Technical support provided before the next dialysis is scheduled when problems are encountered.
- The ability to accommodate patients for respite care when home support is interrupted or through loss of confidence or the need for additional training.

#### Other services including:

- Patient /carer information
- Psycho-social support
- Nutrition and dietetic services
- Anaemia management, including intravenous iron (self-administered and provided at home). In line with national guidance, intravenous iron will be delivered in an environment with access to medical equipment (such as a device to deliver epinephrine) that is able to deal with potential side effects and proportionate to the risk of such side effects. Patients should be counselled with respect to the risks of this treatment and signed consent for the treatment should be recorded.
- Blood transfusion and erythropoietin stimulating agents (ESAs) prescribing.
- Access to Renal Patient View (RPV). For those who register with RPV they will be encouraged to advise their GP.
- Hepatitis B immunisation in primary care.

#### Goals

The service provided should be seamless and enable patients to make informed choices about the care they receive.

Full choice of home therapies offered where clinically appropriate.

Facilitate shared decision-making, offering genuine choice for all treatment options.

#### **Initiation of Treatment**

#### Confirmation of modality decision:

HHD should be initiated in a controlled manner with the patient having received appropriate education and support. The decision to commence HHD should be based upon a holistic assessment of the patient, including physical signs and symptoms and competency-based education and should be made by a multi-

disciplinary team.

#### **Home Assessments and Adaptations:**

Every potential home haemodialysis patient is required to have a home assessment. This is to determine the suitability of the patient's home to accommodate the requirements of home haemodialysis including physical space, plumbing and electricity, and should be a joint decision made between the patient and the healthcare team. Tariff payment for home haemodialysis will need to cover the cost of home conversion, remote tele-monitoring where appropriate and decommissioning when no longer required.

Preferred options in priority order are:

- Use of the tray system.
- Adaption of an existing spare room or other suitable space within the patients home.
- Where the above are not practical, then consideration may in exceptional circumstances be given to building adaptations.
- Training on a mobile machine may be considered.
- Adaptations such as conservatories or large extensions should be funded only in exceptional circumstances.
- A close working relationship with estates departments or a local electrician/ plumber at the provider Trusts must be developed to ensure that the most cost effective option is identified.
- Funding for the home adaptations is limited to allow installation of equipment only and for the removal of installed equipment and plumbing services when no longer required.
- It is recognised that there may be circumstances when it is appropriate to make a contribution towards a utility bill if:
  - A patient is running specialised equipment at home, which would usually be operated in a hospital setting; AND
  - There are additional costs of running the equipment over and above the patient's usual utility bills; AND
  - The specialised equipment is the commissioning responsibility of NHS England.

In the case of home dialysis, NHS England will meet (through the payment of the national tariff to the patient's usual dialysis provider) the additional direct utility costs (which may include electricity, water, gas and telephone) by way of a reimbursement to the patient. These costs should be based on documentary evidence such as copies of utility bills before and after the specialised equipment was introduced. The costs should be agreed between the provider and the individual patient.

 In some circumstance it may be helpful for clarity if the patient and the renal centre have a written agreement making clear the specific responsibilities and obligations of each party in regard to the installation and removal of equipment.

#### 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

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. All patients with end-stage kidney disease should be considered for home haemodialysis.

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)

There are no absolute exclusion criteria for assessment except as implied by the NICE Guidance eligibility criteria.

## 3.5 Interdependencies with other services/providers Co-located services

Co-located at training site for home haemodialysis

#### **Interdependent Services**

Medical cover for emergencies

Support at home by the MDT

Pathology

Surgical and Intervention radiology procedures

Psycho-social support

Pharmacy services

Vascular access

Nutrition and dietetic services

Anaemia management

Hepatitis B vaccination

Technical support for machine breakdown/problems

#### **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

Water Boards

Environmental waste service

#### 4. Applicable Service Standards

#### 4.1 Applicable national standards e.g. NICE

A number of documents provide relevant information in relation to home dialysis therapies and should be read in conjunction with this paper.

'Improving choice for HHD' 3

'Five steps toolkit' 4

National Service Framework for Renal Services 6

'Achieving excellence in Kidney Care'7

The National Institute for Health and Clinical Excellence (NICE) technical guidance (TA48) - Home versus Hospital Haemodialysis 8

NICE guideline Anaemia management in people with chronic kidney disease 2011

'Your Health, Your Way: A guide to long term condition & self-care' 9

Renal Association Working Party reports on HHD10 and PD11

### 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   | Threshold                  | Method of Measurement           | Consequence of    |  |
|---|----------------------------|---------------------------------|-------------------|--|
| Requirement   |                            |                                 | breach            |  |
| ·   |                            |                                 |                   |  |
|   |                            |                                 |                   |  |
| Domain 1: Prever  | nting people dying         | prematurely                     |                   |  |
|   |                            | <b>.</b>                        |                   |  |
|   |                            |                                 |                   |  |
| For all suitable  | Benchmark with             | % of patients receiving home    | As per Standard   |  |
| patients to have  | action plans for           | haemodialysis as a % of all     | NHS Contract      |  |
| option of having  | improvement to             | dialysis patients.              | General           |  |
| home  | follow if                  |                                 | Conditions Clause |  |
| haemodialysis   | proportion of              |                                 | 9 (GC9) Remedial  |  |
|   | home                       |                                 | Action Plan       |  |
|   | haemodialysis              |                                 |                   |  |
|   | patients is in             |                                 |                   |  |
|   | lower quartile of          |                                 |                   |  |
|   | national                   |                                 |                   |  |
|   | performance                | Annual audit.                   |                   |  |
| D   | 1 11 11                    |                                 | 1141              |  |
| Domain 2: Enhan   | cing the quality of        | life of people with long-term c | onditions         |  |
|   |                            |                                 |                   |  |
| To increase the   | Donobasouk                 | 0/ of notionto receiving home   | As nor Ctondord   |  |
| To increase the   | Benchmark                  | % of patients receiving home    | As per Standard   |  |
| number of   | followed by                | haemodialysis as a % of all     | NHS Contract      |  |
| patients  | action plans for           | dialysis RRT patients.          | General           |  |
| accessing home  | improvements if            |                                 | Conditions Clause |  |
| haemodialysis.  | proportion of              |                                 | 9 (GC9) Remedial  |  |
|   | home                       |                                 | Action Plan       |  |
|   | haemodialysis              |                                 |                   |  |
| V   | patients is in             |                                 |                   |  |
|   | lower quartile of national | Annual audit                    |                   |  |
|   | performance                |                                 |                   |  |
|   | Penomiance                 |                                 |                   |  |
| Domain 3: Helping people to recover from episodes of ill-health or following injury |                            |                                 |                   |  |
|   |                            |                                 |                   |  |
|   |                            |                                 |                   |  |

| Quality<br>Requirement   | Threshold  | Method of Measurement  | Consequence of breach  |  |
|--|--|--|--|--|
| To ensure patients are informed and involved in their care.                    | Benchmark<br>followed by<br>action plans for<br>improvement. | % of patients who complete education/training programme including repeat sessions/further education.  Evidence of outcomes from  | As per Standard<br>NHS Contract<br>General<br>Conditions Clause<br>9 (GC9) Remedial<br>Action Plan |  |
|  |  | education sessions.  Annual Audit.   |  |  |
| Domain 4: Ensurin  | ng that people hav   | ve 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.         | 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.  2. Number and % of patients with access and instruction in the use of Renal Patient View.  3. Number and % of patients utilising shared decision making aids/actively involved | As per Standard<br>NHS Contract<br>General<br>Conditions Clause<br>9 (GC9) Remedial<br>Action Plan |  |
| Domain 5: Treatin  | g and caring for p   | in shared decision making.   | nd protecting them   |  |
| from avoidable harm  |  |  |  |  |
| To have relevant MDT and services available to support and ensure the safety   | In place for all units with home haemodialysis patients      | Evidence of MDT and service available, including arrangements for 24/7 cover.  Evidence of access to respite   | As per Standard NHS Contract General Conditions Clause 9 (GC9) Remedial                            |  |

| Quality<br>Requirement  | Threshold | Method of Measurement  | Consequence of breach |
|-------------------------|-----------|--|-----------------------|
|                         |           |  |                       |
| of the patient at home. |           | care, available at short notice if necessary.  Annual audit. | 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 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.
- o Families with children have easy access to hospital facilities for children without needing to travel significantly further than to other similar amenities.
- o 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. All UK anaesthetists undergo training which provides them with the competencies to care for older babies and children with relatively straightforward surgical conditions and without major co-morbidity. However those working in specialist centres must have undergone additional (specialist) training<sup>2</sup> and should maintain the competencies so acquired<sup>3</sup> \*. These competencies include the care of very young/premature babies, the care of babies and children undergoing complex surgery and/or those with major/complex co-morbidity (including those already requiring intensive care support).
- As well as providing an essential co-dependent service for surgery, specialist anaesthesia and sedation services may be required to facilitate radiological procedures and interventions (for example 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 principals 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.

- o Taking action immediately to ensure that any abuse identified is stopped
- o 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.
- o 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.
  - o 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.
  - o 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 III 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:
  - o 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