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# SCHEDULE 2 – THE SERVICES

#### Α. Service Specifications

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Craniofacial Service (All Ages)
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#### 1. Population Needs

#### 1.1 National/local context and evidence base

Craniofacial surgery is delivered by a multi-disciplinary team (MDT) for the treatment of major anomalies involving the cranium, the face, and associated structures. These anomalies may arise from tumours, trauma or predominantly congenital developmental malformation and may have very complex management needs.

The clinical groups requiring highly specialised paediatric craniofacial care were defined in the document EL98 (1) in appendix 2. Between 1988 and 1997, four specialist units were designated and have now undergone a lengthy maturation process.

The services provide for the assessment, surgical treatment and long term follow up of patients with congenital combined cranial and facial deformities which require holistic patient management within an MDT, in line with the National Craniofacial Standards 2011.

National audit data for the last 2 years indicate that the four units treated 289 referrals and 301 primary presentations, for cranio-synostosis (including the cranio-facial dysostoses).

#### The diagnostic groups consist of

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- 1. All cranio-synostosis including craniofacial dysostosis syndromes
- 2. Orbital dystopia
- 3. Rare Clefts of the anterior skull base, orbit and face (Tessier craniofacial clefts) excluding cleft lip and palate
- 4. Encepalocoeles

#### 5. Dermoids/craniofacial dysraphia affecting anterior skull base

http://www.specialisedservices.nhs.uk/library/25/National Craniofacial Standards.pdf

The UK national designated craniofacial service is held internationally as a benchmark of service delivery in the optimization of patient care. 'National Craniofacial Service Standards in England', W. Gutteridge, Craniofacial Surgery 11, Coolum, Queensland, Australia, September 11-14, 2005, which allows the delivery of longterm audit data on patient outcome, as well as novel techniques in surgery, basic science research, and mechanisms of service delivery.

# 2. Outcomes

Keholder testi Three nationally agreed CQIN on-going outcome related projects have been agreed. These include :-

- Headspace Project
- **Blood Use Monitoring**
- Patient/Public Experience

#### In addition:

- Patient and service quality measures in place
- Patient Safety is pro-actively monitored
- Patient experience is actively sought and assessed
- Outcome measures are clear
- Service development is in line with new evidence base as it evolves

#### Service monitoring and development

- Attendance at the national Craniofacial Audit Meeting hosted on a rotating basis annually at each designated unit
- Presentation of combined unit activity data to commissioners
- Evidence of collaborative audit between the national centres
- Presentation of complications data according to the Oxford protocol
- Presentation and discussion of mortalities
- Evidence of independent clinical and basic science research
- Presentation of current scientific activity within the four units with special emphasis on improvements in:-

# 2.1 NHS Outcomes Framework Domains & Indicators

Domain 1	Preventing people from dying prematurely	V
Domain	Enhancing quality of life for people with long-	$\checkmark$

2	term conditions		
Domain	Helping people to recover from episodes of ill-	$\checkmark$	
3	health or following injury		
Domain	Ensuring people have a positive experience of	$\checkmark$	
4	care		
Domain	Treating and caring for people in safe	$\checkmark$	
5	environment and protecting them from		
	avoidable harm		20

In addition to the national key performance indicators (eg. waiting times, infection rates) service specific KPI's will monitor that:

- 1. All patients and families have access to a clinical nurse specialist
- 2. The functional outcome of all procedures is recorded by regular monitoring
- Access to patient and family support groups is facilitated
- There is consistency of patient ease of access to multidisciplinary care across the currently designated sites

#### 3.1 Aims and objectives of service

Where possible Craniofacial services will ensure that both proactive and reactive multidisciplinary measures will be taken to safeguard:

- Protection of vital structures
- Preservation of existing function
- Prevention of functional deterioration
- Prevention of progressive deformation
- Correction of established deformity
- Promotion of the psychosocial well-being of the child and family
- Promote the educational development of the child

Cranio-facial services will ensure safe, sustainable management of highly complex patients by :

- Maintaining appropriate skill levels in all team members through volume of activity
- Maintain sustainability of the services by ensuring that work streams are manageable in all eventualities and by appropriate succession planning

Craniofacial services will recognise the impact of having a craniofacial condition upon the individual and the family from birth to maturity. Multidisciplinary care will be provided to allow for the changing needs of the family and individual as the child passes from infancy to adolescence and adulthood and will incorporate transition needs. Patient and family interaction with support groups is a recognised need, and annual joint awayday meetings are held to foster these links between the currently designated units, patients and families, and the various national support groups. Opportunity is taken to explain the philosophy and evidence base of care, and respond to comments/concerns on service provision and patient experience.

# 3.2 Service description/care pathway

The cranio-facial surgery service is designated to treat **all** patients with congenital cranio-facial conditions as referenced in EL(98)1 when they are:

- Complex
- Involve the base of the skull and
- Treatment will require, at an appropriate stage, a combined craniofacial procedure as described above.

The service covers referral for assessment of all patients suspected of having one of the following diagnoses, and the treatment and associated follow up of all those in whom the condition is confirmed:

The diagnostic groups consist of:

- 1. All Craniosynostosis including Craniofacial Dysostosis syndromes
- 2. Orbital dystopia
- 3. Rare Clefts of the anterior skull base, orbit and face ('Tessier craniofacial clefts') excluding cleft lip and palate
- 4. Encepalocoeles

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5. Dermoids/craniofacial dysraphia affecting anterior skull base

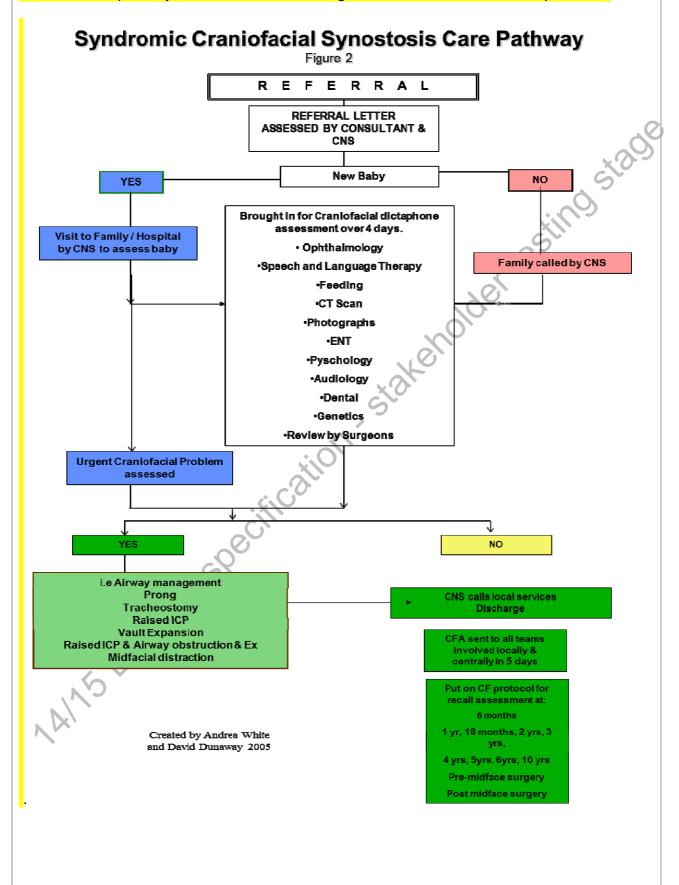
#### **Genetics service**

Research activity conducted within the existing four designated units has defined genetic causation as a fundamental element of overall craniofacial care. This essential component of the service informs patients of their future expectations, management plans and what to expect from their treatment and eventual outcome. Genetic testing takes place to identify cases with a possible genetic diagnosis and should be offered to all children and their families with a craniofacial condition where the clinical picture or family history suggests a possible genetic link.

This is an essential component of the service which informs patient expectations, management plans and expectations of outcome. Genetic testing takes place to identify cases with a possible genetic diagnosis and should be offered to all children and their families with a craniofacial condition where the clinical picture or family history suggests a possible genetic link.

**Craniofacial Care Pathways** 

All craniofacial pathways will be consistent with agreed national standards. Example below.



Initial access is via a consultant clinic, whereupon a care plan and initial investigations are instituted. These are reviewed by the multidisciplinary team with regular (weekly) team meetings. The care plan is reviewed and refined as required, with sign off, and communication with the patient is facilitated by the clinical nurse specialist. Appointments for investigations, surgeries and follow ups as required are set and travel and accommodation for patients and families facilitated as required and detailed according to specific need and centre of care. Post – procedure follow up and investigation as required are by protocol and adjusted for specific need where necessary. Multi-disciplinary appointments are co-ordinated to minimise the impact of travel etc. upon the patient and family.

#### Data Management, Audit and Governance

Data management, audit and governance will take place in accordance with the Craniofacial Standards (2011). The national audit meeting has been running for several years, with regular refinement of format, standardisation of datasets and presentation format, and discussion of outcome and SUIs. The format, in the presence of the Commissioners, incorporates audit and academic content.

#### Service model

The service comprises regular multi-disciplinary (MDT) assessment from birth to maturity where required genetic testing, surgical corrections as appropriate and long term follow up. It is recognised that the needs of the craniofacial child and family change with increasing maturity and development and the changing developmental pathology of the conditions treated. Regular patient assessment is tailored to these requirements in terms of frequency, content and timing; and with due attention to the 'burden' of care and practical considerations of patient experience.

#### Transition from paediatric to adult services

Providers will ensure a smooth transition for patients moving from children's to adult services. This will include specific information for patients on how transition arrangement are organised and where appropriate the establishment of joint clinics with the input from members of both children's and adult multi disciplinary teams. Processes are in place to receive feedback from patients on how these arrangements are working, with a regular assessment of patient reported experience

#### Referral processes and sources

The craniofacial service is currently nationally designated according to the model of one service on four sites. This allows access to all craniofacial units according to patient choice : Referrals include:-

- GP Referral
- Referral from secondary care
- Referral from another tertiary provider

# Discharge criteria and planning

The service offers patients holistic care through a MDT approach. Patents will be consulted and involved in their long term support through transition to adulthood and upon discharge from the service, recognising the requirements of care change with the age of the patient and the natural history of the conditions treated. Long term access to genetic counselling will also be offered on discharge.

#### **Patient-Centred Services**

Holistic patient and family orientated care is the foundation of the national craniofacial services. Access is facilitated by support by named craniofacial nurse specialists and regular co ordination with Craniofacial Patient Support Groups. Craniofacial service provision will be designed and referenced by regular Patient feedback assessment of both outcome and experience. All patients have direct access to a designated clinical nurse specialist, and thereby consultant input from the appropriate arm of the MDT at all times during their care. Where the needs of the family change, such as in domestic relocation, communication in transfer of care centre is facilitated for smooth information exchange between the care centres in the patient interest.

# **Operational Delivery Network (ODN)**

Craniofacial care provides a benchmarked standard of care for craniofacial patients on four , 101der test nationally linked sites which include:

- Adherence to agreed quality standards
- **Operational delivery pathways**
- Patient experience and outcome measures
- Equality of access
- Patient Safety
- The reporting of Serious Untoward Incidents

The service is responsive to changes in patient need, and has been responsive to patient and family led requests for information on clinical care pathways, individual surgical procedures, and change of service delivery, as services have developed.

#### 3.3 Population covered

England, Wales and Northern Ireland

Patient access is facilitated by the siting of the four service centres across the UK at:

Alder Hey Children's NHS Foundation Trust, Liverpool Birmingham Children's Hospital, Birmingham Great Ormond Street Hospital for Children, London Oxford University Hospital, Oxford

# 3.4 Any acceptance and exclusion criteria and thresholds

Patients accepted to the service must meet definitions described in the scope of the service and referenced in EL98 (1), appended.

Referrals may be accepted for the assessment of children and families to each centre from primary or secondary care referrers, across the UK. The transfer of patients between centres is occasionally requested, and is facilitated by the transfer of information between teams where required. Second opinion services are supported where requested by patients and families, and are sought between teams where clinical decision – making is particularly complex.

Providers require staff to attend mandatory training on equality and diversity and the facilities provided offer appropriate disabled access for patients, family and carers.

When required the providers will use translators and printed information is available in multiple languages.

The provider has a duty to co-operate with the commissioner in undertaking equality impact assessments as a requirement of race, gender, sexual, orientation, religion and disability equality legislation.

# 3.5 Interdependencies with other services/providers

These will be consistent with agreed National Craniofacial Standards (2011), appended. Craniofacial patients and families are recognised to interface with many care - givers in the hospital and outside hospital environments. Communication between the various care – givers is key and a risk factor to the smooth experience of the patient and family. Where particularly complex care by multiple agencies is likely, these families will be noted for the avoidance of potential risk events in the interlinking patient pathway.

## **Data Submission**

There will be joint annual activity and outcome data submission according to an agreed protocol as defined in the craniofacial standards (2011), appended. Data includes annual activity, risk events, service developments, patient reported parameters and academic activity.

# 4. Applicable Service Standards

National Standards in Craniofacial Surgery Revised 2011

# 4.1 Applicable national standards e.g. NICE

The providers of the national craniofacial service must ensure they are fully integrated into their provider's corporate and clinical governance arrangements and must comply fully with Clinical Negligence Scheme for Trusts (CNST) and Care Quality Commission (CQC) requirements in terms of quality and governance.

Each centre will ensure that there are:

- Regular meetings with patient representatives
- All practitioners will participate in continuous professional development and networking
- Patient outcome data is recorded and audited across the service.

# **Risk management**

Patient care delivered by the craniofacial surgery service providers must meet the Craniofacial Standards (2011) in line with the service specifications and agreements. It is the service provider's responsibility to notify the commissioner on an exceptional basis should there be any breaches of the care provision, or patient management standards. If there are breaches the provider is responsible for the resolution.

Where a patient's presentation challenges the assumptions that underpin the specification, service standards and contractual arrangements it is the providers responsibility to inform the commissioners.

#### 5. Applicable quality requirements and CQUIN goals

Quality Performance Indicator	Method of measurement	Report Due
Blood loss per patient. – using the Alder Hey Liverpool protocol (e.g. % of red cell volume used/donor exposure etc.)	Blood tests	annually
Multi Unit Investigation of Patient Reported Outcomes (PROMs) – e.g on going patient appearance based outcome.	Questionnaire	annually
All surgical complications are to be reported to NHS England using the Oxford Protocol	Data submission	annually

Current CQUIN goals relate to patient satisfaction, blood use monitoring, and the 'Headspace project' which evaluates a 3D photography tool, for the purpose of the standardisation of results, and the acquisition of normative data. (An initial report was prepared for the half year 2013/4, and is to be repeated annually of further goals as they are developed)

# 6. Location of Provider Premises

# The Provider's Premises are located at:

Alder Hey Children's NHS Foundation Trust, Liverpool Birmingham Children's Hospital Great Ormond Street Hospital for Children, London Oxford University Hospital .

# Appendix One

# Quality standards specific to the service using the following template:

Quality Requirement	Threshold	Method of Measurement	Consequence of breach					
Domain 1: Preventing p	eople dying premature	ly						
Death	Zero mortality	Mortality rate	Death = SUI. Trigger a root cause analysis as an unanticipated event					
Domain 2: Enhancing the quality of life of people with long-term conditions								
Entry to independent adult life	Establish rate	Patient Quality of Life questionnaire	Audit to evaluate causation and address deficiencies in required support					
Domain 3: Helping people to recover from episodes of ill-health or following injury								
Access to multidisciplinary craniofacial assessment	Improvement of parameters after care event: ie. airway analysis, intracranial hypertension	Outcome of care event: sleep study, assessment of ICP, vision.	Audit to establish causation and establish change of practice if required					
Domain 4: Ensuring that people have a positive experience of care								
Ensure all patients have access to a named clinical nurse specialist	>95%	Proportion of patients who have access to a craniofacial clinical nurse specialist	Audit to establish causation and establish change of practice if required					
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm								
Compliance with National and Trust approved KPI's	Established KPI's	Reporting of adverse or risk events by Trust guideline	As per KPI guidelines					

#### Appendix 2 – EXTRACT FROM EL (98)1 JANUARY 1998 ANNEX D CRANIOFACIAL SURGERY SERVICE

#### SERVICE DEFINITION (with effect from 1.4.98)

#### Background

As a result of congenital disease, tumour or trauma, patients may have or develop problems which involve both the floor of the skull and the bones and issues of the face. When the condition is severs it will require corrective treatment which will involve, at an appropriate state, at least one complex major surgical procedure. The procedure comprises a combined approach by at least two surgeons. A neurosurgeon will need to open the skull, particularly thee front part (anterior fossa). At the same time a plastic or maxillofacial surgeon will expose the bones of the upper face (including the maxilla and eye sockets). Many of the bones will have to be separated, manipulated, repositioned and fixed into place with wires or plates made for the individual patient. Some bone and other tissues may have to be removed. Preoperative planning, peri and post operative care have to be of high order particularly when the patient is a baby or young child. Multidisciplinary teamwork is essential.

Such operations on children are complicated by the fact that development of the facial bones will continue for many years and the final outcome may not be known until adulthood is reached. Many of the congenital craniofacial conditions (see below) have a genetic origin so the overall management of the patient may require a genetic diagnosis. Such conditions are rare and considerable experience is required to determine the optimum time to operate (in some cases a delay of months or a year or more are advisable, others should be corrected early) and the exact type of procedure to be performed. Long term follow up is essential and a number of other corrective procedures may be required.

#### The designated service

The craniofacial surgery service is designated to treat all patients with the congenital craniofacial conditions listed below when they are complex, involve the base of the skull and treatment will require, at an appropriate stage, a combined craniofacial procedure as described above. The service covers referral for assessment of all patients suspected of having one of the following diagnoses, and the treatment and associated follow up of those in whom the condition is confirmed.

# CRANIOSYNOSTOSIS

Sagittal scaphocephaly (rarely) Uniteral coronal plagiocephaly Bilateral coronal brachycephaly Metopic trigonocephaly Lambdoid synostosis (rarely) Total craniosynostosis

#### **CRANIOFACIAL DYSOSTOSIS**

Crouzon's Syndrome Acrocephalo-syndactyly syndromes Apert's Saethre-Chotzen Pfeiffer Carpenter etc.

# **ORBITAL DYSTOPIA**

Horizontal and Vertical

**ENCEPHALOCELE** – involving the skull base.

#### Appendix 3

### 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 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.

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- Families with children have easy access to hospital facilities for children without needing to travel significantly further than to other similar amenities.
- Children are discharged from hospital as soon as socially and clinically appropriate and full support provided for subsequent home or day care.
- Good child health care is shared with parents/carers and they are closely involved in the care of their children at all times unless, exceptionally, this is not in the best interest of the child. Accommodation is provided for them to remain with their children overnight if they so wish.

#### Service description/care pathway

All paediatric specialised services have a component of primary, secondary, tertiary and even quaternary elements.

The efficient and effective delivery of services requires children to receive their care as close to home as possible dependent on the phase of their disease.

Services should therefore be organised and delivered through "integrated pathways of care" (National Service Framework for children, young people and maternity services (Department of Health & Department for Education and Skills, London 2004)

# Interdependencies with other services

All services will comply with *Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies* – Department of Health (DH)

# Imaging

All services will be supported by a 3 tier imaging network ('Delivering quality imaging services for children' DH 13732 March 2010). Within the network:

- It will be clearly defined which imaging test or interventional procedure can be performed and reported at each site
- Robust procedures will be in place for image transfer for review by a specialist radiologist, these will be supported by appropriate contractual and information governance arrangements

- Robust arrangements will be in place for patient transfer if more complex imaging or intervention is required
- Common standards, protocols and governance procedures will exist throughout the network.
- All radiologists, and radiographers will have appropriate training, supervision and access to continuing professional development
- 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 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 for the Provision of Anaesthetic Services (GPAS) Paediatric anaesthetic services. RCoA 2010 <u>www.rcoa.ac.uk</u>

2. Certificates of Completion of Training (CCT) in Anaesthesia 2010

Continuing Professional Development (CPD) matrix level 3

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

The age profile of children and young people admitted to specialised CAMHS day/inpatient 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/guality/
  - (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:
  - a. having clear procedures followed in practice, monitored and reviewed that take account of relevant legislation and guidance for the management of alleged abuse
  - b. 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
  - c. reporting the alleged abuse to the appropriate authority
  - d. 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,

Care Quality Commission, London 2010

All children and young people who use services must be:

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

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

# **Key Service Outcomes**

Evidence is increasing that implementation of the national Quality Criteria for Young People Friendly Services (Department of Health, London 2011) have the potential to greatly improve patient experience, leading to better health outcomes for young people and increasing socially responsible life-long use of the NHS.

Implementation is also expected to contribute to improvements in health inequalities and public health outcomes e.g. reduced teenage pregnancy and STIs, and increased smoking cessation. All providers delivering services to young people should be implementing the good practice guidance which delivers compliance with the quality criteria.

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

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

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

- A16.1 Children are seen in a separate out-patient area, or where the hospital does not have a separate outpatient area for children, they are seen promptly.
- A16.3 Toys and/or books suitable to the child's age are provided.
- A16.8 There are segregated areas for the reception of children and adolescents into theatre and for recovery, to screen the children and adolescents from adult patients; the segregated areas contain all necessary equipment for the care of children.
- A16.9 A parent is to be actively encouraged to stay at all times, with accommodation made available for the adult in the child's room or close by.
- A16.10 The child's family is allowed to visit him/her at any time of the day, except where safeguarding procedures do not allow this
- A16.13 When a child is in hospital for more than five days, play is managed and supervised by a qualified Hospital Play Specialist.
- A16.14 Children are required to receive education when in hospital for more than five days; the Local Education Authority has an obligation to meet this need and are contacted if necessary.
- **A18.10** There are written procedures for the assessment of pain in children and the provision of appropriate control.

All hospital settings should meet the Standards for the Care of Critically 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 hydraton that mett any reasonable reuirements 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:

• They are supported to have a health action plan

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- 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. Improvng the transition of young people with long-term conditions from children's to adult health services. Department of Health, 2006, London.