

E02/S(HSS)/d

**2013/14 NHS STANDARD CONTRACT  
FOR CRANIOFACIAL SERVICE (All Ages)**

**PARTICULARS, SCHEDULE 2- THE SERVICES, A. SERVICE SPECIFICATIONS**

<b>Service Specification No.</b>	E02/S(HSS)/d
<b>Service</b>	Craniofacial service (All Ages)
<b>Commissioner Lead</b>	
<b>Provider Lead</b>	
<b>Period</b>	12 months
<b>Date of Review</b>	

**1. Population Needs**

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

The craniofacial service may be defined as a surgical discipline practiced by a multi-disciplinary team for the treatment of major anomalies involving the cranium, the face, and associated structures, in a variety of combinations.

The service provides for the assessment, surgical treatment and long term follow up of patients with congenital combined cranial and facial deformities requiring management within a multidisciplinary team. The multi-disciplinary team consist of a wide range of clinicians and therapists.

**2. Scope**

**2.1 Aims and objectives of service**

The aims of the service are as follows:

- 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.

### **2.1.1 Scope**

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

- Complex
- Involve the base of the skull and
- Treatment will require, at an appropriate stage, 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.

#### Craniosynostosis craniofacial dysostosis

Sagittal scaphocephaly

Unilateral coronal plagiocephaly

Bilateral coronal brachycephaly

Metopic trigonocephaly

Lambdoid synostosis

#### Acrocephalo-syndactyly syndromes

Apert's

Saethre-Chotzen

Pfeiffer, Carpenter

#### Craniofacial dystosis

Crouzon's Syndrome

#### Orbital dystopia

Horizontal and Vertical

#### Encephalocele

### **Genetics service**

There is an important genetic component to the service. 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.

### **2.2 Service description/care pathway**

The service comprises genetic testing, assessment, surgical corrections and follow up.

### **Transition from paediatric to adult services**

Providers are expected to ensure a smooth transition for patients moving from

children's to adult services. This should include specific information for patients on how transition arrangements 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 should be put in place to receive feedback from patients on how these arrangements are working.

### **2.3 Population covered**

NHS England commissions the service for the population of England.

At the moment, this Service Specification includes provision for the service to treat eligible overseas patients under S2 [Under UE regulations, patients can be referred for state funded treatment to another European Economic Area (EEA) member state or Switzerland, under the form S2 (for EU member states) or the form E112 (for Iceland, Norway, Liechtenstein and Switzerland)] referral arrangements. Providers are reimbursed for appropriately referred and recorded activity as part of the NHS England contract.

Trusts performing procedures on EU-based patients outside of S2 arrangements will need to continue to make the financial arrangements directly with the governments involved, separately from their contract with the NHSE.

With regards to S2, the mechanism for recovery of costs has been via the Department for Work and Pensions overseas healthcare team. They are responsible for agreeing reconciliation and recovery of costs with European administrations. These arrangements were implemented in October 2009, though a similar process existed previously. The financial flows are therefore back into the Treasury rather than back to trusts.

Changes to the existing arrangements recommended in Allocation of organs to non-United Kingdom (UK) EU residents are under consideration by the Department of health as part of a wider review of eligibility, allocation and funding of deceased organs donated for transplantation.

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

Patients accepted to the service must meet definition described in the scope of the service and set out in EL98 (1) – see Appendix A

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. Applicable Service Standards

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

##### Risk management

Care delivered by the craniofacial surgery service providers must be of nature and quality to meet the care standards, specification and agreement for the service. It is the trust's responsibility to notify the commissioner on an exceptional basis should there be any breaches of the care standards. Where there are breaches any consequences will be deemed as being the trust's responsibility.

Patients must be managed in line with the specification and care standards. Any deviation from these which has not been approved by the NHS England is at the trust's risk both clinically and financially. It is the trust's responsibility to inform the commissioners of any such non-approved deviations on an exceptional basis.

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

### 4. Key Service Outcomes

Quality Performance Indicator	Threshold	Method of measurement	Consequence of breach	Report Due
Blood loss per patient. – using the Alder Hey Liverpool protocol (e.g. % of red cell volume used/donor exposure etc.)				annually
All units to ask aesthetic questions to patients: <ul style="list-style-type: none"> <li>How pleased are you with your appearance?</li> <li>How noticeable are you to other people?</li> </ul>				annually
All surgical complications are to be reported to NHS				annually

## **APPENDIX A – 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 severe 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 the 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)  
Unilateral 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.

Adopted