

Headlines Information Sheet No 6



National Commissioning and the Four Designated Craniofacial Units

National Commissioning is part of the NHS. They are responsible for funding, managing and developing 'specialised services'. They advise the Ministers on arrangements for the provision of highly specialised services and on the funding required for those services, which are funded centrally and overseen by National Specialised Commissioning Team (NSCT).

There are four centres, nationally designated, to provide specialist services for Children and Adults born with craniofacial problems in the United Kingdom

- Birmingham Children's Hospital
- Great Ormond Street Hospital, London
- Oxford Children's Hospital
- Royal Liverpool Children's Hospital (Alder Hey)

The purpose of the nationally designated service is to make sure that anyone affected by a Craniofacial condition can be seen by an appropriate hospital. Below is the directive, issued by the NSCT, which defines who should be referred to one of the designated units:

The Craniofacial Surgery Service provides assessment, surgical and non-surgical treatment and long term follow-up of patients with congenital deformities of the skull and face. Around 330 complex procedures are undertaken per year.

This service has been nationally designated and commissioned since April 1988 on behalf of the residents of England, Scotland, Wales and Northern Ireland.

The NHS centrally funds four expert centres to assess, manage and follow up patients with complex disorders of the face and skull. In order to obtain good outcomes for patients with these conditions it is essential to have well functioning team that include a wide range of professionals. And the major operations that these patients need often require at least two surgeons from different surgical disciplines to operate at the same time.

The craniofacial surgery service is designated to treat all patients with the congenital craniofacial conditions listed below when they are complex, and treatment will require, a combined craniofacial procedure. 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

Saittal scaphocephaly, Crouzon's Syndrome, Unilateral coronal plagiocephaly, Bilateral coronal brachycephaly, Acrocephalo-syndactyly syndromes, Metopic trigonocephaly, Apert's, Lambdoid synostosis, Saethre-Chotzen, Total craniosynostosis, Pfeiffer, Carpenter

ORBITAL DYSTOPIA

ENCEPHALOCELE - involving the skull base

Most patients referred to the service are children under the age of two, but care may continue into adulthood and a few patients are referred for the first time as adults.

The service includes:

- Diagnosis and assessment that involves specialist techniques to define the nature of the problem (imaging; genetic studies; assessment of speech, language and swallowing; clinical psychology; ophthalmology; audiology) and the type and timing of surgery as some operations are better performed soon and others need to be planned around the development of the child
- Surgery: the main components are neurosurgery, plastic and maxillo-facial surgery, but orthodontics and ENT may also be involved
- Non-surgical treatment: clinical psychology, speech and language therapy

What if you are not at one of the four units, but have one of the conditions, specifically mentioned above?

NSCT would like to ensure that all patients with 'qualifying' conditions have access to treatment at one of the four designated units. **Headlines** is well aware that a number of families with such conditions do NOT attend one of these units. It may be because they aren't aware they have that option, or it may be that they are entirely happy where they are, for a variety of very valid reasons.

If you have not yet been referred to one of the designated units and need some help, please contact Headlines (see below). Either your GP or Paediatrician can refer you to a Craniofacial Unit (**Note:** GOSH will not accept a GP referral). They are often not aware that there is no cost to their Primary Care Trust associated with referring anyone with Craniosynostosis or a Craniofacial syndrome to one of these four centres. In fact, the funding for the four centres has already been made available from the overall National Health Budget via NSCT.

If you are happy where you are, but after reading all this, you need reassurance that you are being seen by the most appropriate type of hospital, please get in touch with your consultant. Feel free to contact us here at Headlines as well. We would be very interested to hear any comments or concerns you may have on this subject.

NSCT are very interested in any feedback we can give them about your experiences at the four units. This is absolutely **NOT** a type of complaints process. It's about highlighting areas of excellence and areas where there is room for improvement and sharing this feedback with the four units, so that hopefully everyone can benefit.

One of NSCT's visions is for the four units to provide as equal a service as possible.

The addresses of the four National Craniofacial Units set up by National Commissioning, are:

Alder Hey Children's Hospital
Eaton Road, West Derby
LIVERPOOL, L12 2AP
Phone: +44(0)151 252 5025

Birmingham Children's Hospital
Steelhouse Lane,
BIRMINGHAM, B4 6NN, UK.
Phone: +44(0)121 333 8147

Great Ormond Street Hospital for Children
Great Ormond Street,
LONDON, WC1N 3JH
Phone: +44 (0)207 813 8444

Oxford Children's Hospital
LG1 West Wing
John Radcliffe Hospital
OXFORD, OX3 9DU.
Phone: +44 (0)1865 231085

The NSCT website is
www.specialisedservices.nhs.uk

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Other leaflets and help are available from Headlines - Craniofacial Support.
Please contact Gil Ruff (Group Administrator) for details.
tel: 01454 850557 or email: gilruff@headlines.org.uk