

D07/S/a

**NHS STANDARD CONTRACT
FOR CLEFT LIP AND / OR PALATE SERVICES INCLUDING NON-CLEFT
VELOPHARYNGEAL DYSFUNCTION (VPD) (ALL AGES)**

SCHEDULE 2 – THE SERVICES A. SERVICE SPECIFICATIONS

Service Specification No.	D07/S/a
Service	Cleft Lip and / or Palate Services including Non- Cleft Velopharyngeal Dysfunction (VPD) (All Ages)
Commissioner Lead	
Provider Lead	
Period	12 months
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

One in 600-700 babies is born with Cleft Lip and/or Palate malformations, the most common congenital abnormality in the cranio-facial region. The incidence is approximately 1.6 per 1,000 but this can vary year to year.

Many patients suffer from impaired facial growth, dental anomalies, speech disorders, poor hearing and difficulties in psychological well-being and social relationships.

In round figures, the incidence of CLP may be summarised as follows in:

- Cleft Palate only 45%
- Cleft Lip (+/- alveolus) only 23%
- Unilat Cleft Lip and Palate 22%
- Bilateral Cleft Lip and Palate 10%

The patient pathway extends from pre-birth to adult life and a typical cleft team will treat and monitor several thousand patients at any moment in time, with a number of patients returning for treatment in adulthood.

Techniques in cleft care have advanced over recent years and adult patients who have received surgery in the past sometimes require further specific intervention from the CLP teams to optimise previous procedures.

Evidence Base

The Clinical Standards Advisory Group (CSAG) Report 1998 summarises the key issues and challenges to be addressed by providers and commissioners.

The key service policy and legislative documents which support the provision of high quality Cleft Lip and Palate services are listed below. The specification is not intended to duplicate, replicate or supersede these policies and guidelines but to build upon them. The Care Standards Act (2000) is a foundation document across all specifications.

National Institute for Health and Clinical Excellence (NICE) Guidance

- NICE guideline 60 'Surgical management of otitis media with effusion in children' Feb.2008 section 1.8

Service / Patient Group Guidance

- CLAPA Report on 'Regionalisation of Cleft lip and palate services: has it worked?' April 2007

Department of Health (DH)

- DH Clinical Standards Advisory Group report into Cleft Lip and Palate 1998
- Health Service Circulars (HSC) 1998/002
- HSC 1998/087
- HSC 1998/238 *Cleft lip and palate services - commissioning specialised services*
- DH The NHS Outcomes Framework
- DH letter 29th August 2001
- DH letter on Guidance on making appointments to new cleft centres

Other Key Documents

- Minimum standards for the management of cleft lip and palate: efforts to close the audit loop. Shaw WC et al, Ann R Coll Surg Engl 1996; 78: 110-114
- Specialised Services National Definitions Set (SSNDS)(3rd edition) No.15: Cleft Lip and Palate Services (all ages)
- SSNDS (3rd edition) No.20 Specialised Medical Genetics Services (all ages)
- SSNDS (3rd edition) No.23 Specialised Services for Children
- Craniofacial Anomalies Network (CRANE) Annual Report 2011

- Cleft Palate and Velopharyngeal Disorders' in 'Communicating Quality 3' - The Royal College of Speech and Language Therapists (RCSLT's) guidance on best practice in service organisation and provision 2006 p.288-296 Published by RCSLT
- Getting the right start: National Service Framework for Children. Standard for Hospital Services. 2003

2. Outcomes

2.1 NHS Outcomes Framework Domains & Indicators

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

Data collection for the Craniofacial Anomalies Register (CRANE Database)

All Hubs providing Cleft care are required to and currently do submit information to CRANE. This database is commissioned by SCGs and produces both annual and interim reports. Commissioners are able to request specific queries to CRANE to aid commissioning. CRANE data analysis is also reported to the national Cleft Development Group who use the information to drive quality services and interrogate variation. The following outcomes are collected: details of diagnosis and appropriate/timely referral from maternity units to Hubs; key outcome indicators at 5 years of age, including facial growth, speech, dental disease and overall growth with height and weight data. Key indicators will also be developed and included for a variety of ages including 10, 15 and 20 year olds.

In addition, the CRANE Project Team also produces analyses of data from the Hospital Episode Statistics (HES), the database on all NHS hospital admissions in England and

Patient Episode Data Wales (PEDW) for all NHS hospital admissions in Wales. These data are used to provide additional information including: hospital and surgeon volumes for surgical procedures; number of hospital admissions and length of stay in hospital; readmission rates; emergency admission rates. This will develop further to include reporting outpatient episodes of care.

Service outcomes

The aims of treatment of CLP are to ensure that children and adults:

- Who have a cleft lip repair, have a good aesthetic and functional result
- Who have a palatal cleft repair, have good palate function to produce good speech, normalised hearing and optimal dento-facial development including jaw growth.

They should be able to function well socially and without disadvantage. The aim of treatment of non-cleft VPD is to improve speech.

In some of these areas of clinical outcome, robust and validated outcome measures have been developed and are in routine use through local, regional, national and international audit. This service specification includes 42 Standards of Care (section 4.1) which relate to process and clinical outcome in the management of Cleft Lip and / or Palate and non-Cleft Velopharyngeal Dysfunction. The outcome measures referred to in this document are all ones which are robust and have been validated. Unfortunately there are some clinical areas where such outcome measures are not yet adequately developed anywhere in the world (for example, assessment of the result of lip repair) but work is on-going especially in the UK Cleft Special Interest Groups of the Craniofacial Society of Great Britain and Ireland and nationally in the CRANE project team to develop these measures.

The CRG has developed a dashboard that contains measures reflecting elements of the MDT's Cleft care. All CLP outcomes are in Domain 2 of the NHS Outcomes Framework (Enhancing quality of life for people with long-term conditions).

Domain 2 : Enhancing quality of life for people with long term conditions

1. Outcome: 100% of families are supported by the CLP Clinical Nurse specialist (CNS) at an early stage following diagnosis.
Measures: % of parents contacted by the Cleft team CNS within 24 hrs of notification of an antenatal diagnosis of CLP
% of families that receive a visit from a Cleft team CNS for advice within 24 hours of first referral at birth or first diagnosis after birth.
2. Outcome: All babies with CLP receive initial lip and palate surgery at the optimal time to achieve best results.
Measures: Number of babies receiving first lip repair by 6 months of age, in the

absence of specific clinical reasons for delay (e.g. syndromes, co-morbidity and approved research)

Number of babies receiving first palate repair by 13 months in the absence of specific clinical reasons for delay (e.g. syndromes, co-morbidity and approved research)

3. **Outcome:** 100% of all 5 year old children with CLP will have had hearing issues addressed.

Measure: % of all 5 year old children (i.e. over 5 years and under 6 years) with a cleft palate (including cleft lip and palate) who have had their hearing assessed and a plan made to address any hearing issues that have been found

4. **Outcome:** All children with CLP at 5 years of age will have dental health which is at least as good as that of children without CLP in their region.

Measure: Average dmft and treatment index scores of 5 year old children with any cleft (from 5th birthday and before 6th birthday)

5. **Outcome:** Children with CLP achieve good quality, intelligible speech between the age of 5 and 6 years.

Measures: % of children between 5 years of age and before 6 years of age whose speech has no evidence of a structurally related problem and who have not had VP surgery or fistula repair for speech (green outcome on CAPS A section 3 & 4 - % of children between 5 years of age and before 6 years of age who have no cleft speech characteristics (CSCs) which require therapy (with green outcome on CAPS A section 7a)

6. **Outcome:** Children with UCLP have good maxillary growth and achieve good facial appearance

Measure: The 5 year Olds' Index as indicator of maxillary growth in patients with complete UCLP (either no Simonart's band or a band <5mm in height)

7. **Outcome:** All children with CLP achieve psychological well-being.

Measure: % of all children with clefts and their families born in a designated year who have been screened for psycho-social issues by a specialist cleft clinical psychologist at least once before the child's 6th birthday and a plan made to address any issues that arise.

8. **Outcome:** All children requiring alveolar bone grafting will receive that treatment at optimum times and with good results.

Measures: % of children in a single year (2003 births for the first year of the Dashboard) who have an alveolar defect and who are assessed by a cleft team orthodontist and the surgeon responsible for alveolar bone grafting between 7 years and before 9 years of age.

- The Kindelan score (defined) at 6 months post-operative based on an oblique occlusal radiograph of each initial ABG carried out in a designated year as part of their routine protocol of care in children having their first bone graft at less than 16 years of age.

9. **Outcome:** All children with CLP will have acceptable appearance in their permanent dentition.

Measure: Mean Peer Assessment Rating (PAR) scores for completed orthodontic cases in the permanent dentition presented as % PAR

difference for the measured cohort for all cleft types in a designated year.

3. Scope

3.1 Aims and objectives of service

The aim of this service is to provide surgery and specialist care for patients with cleft lip and/or palate and non cleft velopharyngeal dysfunction in order to ensure that patients achieve an aesthetic and functional facial appearance, and to maximise oral feeding, hearing, speech and psycho-social wellbeing.

The service will deliver this aim which will improve the quality of life for children and adults with cleft lip and/or palate (including non cleft VPD) by:

- Offering a safe, clinically effective and accessible service to patients with CLP and their families/carers
- Supporting patients and their families/carers with high quality and appropriate information in a format that meets their individual needs
- Providing patients with timely surgery, treatment and regular follow up in line with the clinical pathway described in this specification.
- Providing a high quality and evidence based service offering effective clinical interventions that ensure optimal clinical outcomes
- Ensuring the entire care pathway is in place for patients
- Facilitating autonomy and transition to adult care
- Supporting patients and families to make informed choices regarding their options using shared decision-making principles and tools to manage their condition to achieve their goals and the best possible quality of life
- Ensuring the CLP services are sensitive to the individual physical, psychological and emotional needs of patients and their families.

3.2 Service description/care pathway

Service description

The provider will provide a comprehensive Cleft Lip and Palate care pathway that comprises of the following elements:

- Prenatal and postnatal diagnosis
- Hospital and community paediatric care
- Pre- and peri-natal specialist cleft nursing including support of newborn feeding and on-going assessment and management

- Genetic assessment and chromosomal studies
- Multi-disciplinary pre-surgery assessment
- Initial lip and/or palate surgery and post-operative assessment
- Paediatric dentistry including dental health education and oral promotion
- Alveolar cleft bone grafting and associated orthodontics
- Cleft-related dento-alveolar surgery
- Velopharyngeal dysfunction (VPD) investigations, therapy, surgery and/or prosthetics with follow-up
- Speech and language assessment and therapy
- Audiology and otology assessment and treatment for hearing problems
- Orthodontics
- Restorative dentistry including implants and prosthetics
- Orthognathic surgery/distraction osteogenesis techniques to correct cleft related jaw deformities, and associated orthodontics
- Rhinoplasty
- Cleft lip and palate revisions and fistula repair
- Psychological care for children, adults and their families
- Revision treatment, which may include surgery, orthodontics and restorative
- Dentistry, in adulthood
- Locally-provided services (e.g. health visitors, children's community services, education, speech and language therapy, primary dental care) supported by the specialist cleft centre team (see Appendix 2, page 36)

Cleft Lip and/or Palate (CLP) is a congenital anomaly resulting from failure of fusion of embryological parts forming the lip, nose and palate. Its management requires the multidisciplinary involvement of many specialties through growth and development to the age of at least 20 years, as well as treatment of adults of any age. Routine care often does not cease at 20 years of age and may continue for a number of further years. Children must be followed up routinely until at least 20 years of age and adults must be able to access and be treated by the service at any age after 20.

Care covers pre-natal and post-natal diagnosis and advice including feeding advice, corrective surgery including specialist and outreach nursing, lip and palate repair, speech assessment, investigation and treatment/surgery, children's dentistry, bone grafting, orthodontics, dento-alveolar surgery, restorative dentistry including implant treatment, rhinoplasty, orthognathic surgery, audiology/Ear Nose and Throat (ENT) (hearing and ENT problems), clinical psychology, genetics, and revision treatment (see National Service Definitions and HSC 1998-238). Delivery of services will be through a network of care managed and often delivered from the specialist centre hub. The network will commonly include outreach and spoke delivery of services and will always rely on strong links with and coordination of local community services. The specialist centre will provide advice, education and support for spoke and community services.

The services also treat and follow-up patients with Velopharyngeal Dysfunction (VPD) whether associated with CLP or independent of it, through assessment, investigation, therapy, surgery and/or prosthetics.

All oro-facial clefts should be diagnosed at birth but there is strong evidence that 35% of isolated clefts of the palate in the UK are diagnosed late because the mouth and palate are not routinely inspected visually at birth.

The service will be safe, of high-quality and evidence-based in line with national policy and guidance. It will offer effective clinical interventions in an appropriate and timely care setting thereby ensuring a positive patient experience and optimal clinical outcomes.

Treatment will be co-ordinated through a dedicated multidisciplinary team of clinicians to achieve optimum outcomes. The team will work with locally identified specialist clinicians (for example Speech and Language Therapists (SLT), orthodontics, ENT and Audiology) when possible or by the centre clinicians working by outreach to ensure the care pathway is in place.

Timely referral and treatment to achieve optimal outcomes across the patient pathway will be required as will close liaison with the patient's General Practitioner and General Dental Practitioner, and non-healthcare professionals, e.g. school authorities. In this respect, treatment will be in line with national policies and guidance (including the report of the Clinical Standards Advisory Group for Cleft Lip and/or Palate and subsequent Health Service Circulars), agreed care pathways and referral criteria.

Services will be provided (where clinically appropriate) at times and ages as required by agreed clinical protocols and within national waiting times on the basis of equity of access based on clinical need for the population served. Centres will contribute to and participate in regional and national audits and contribute data as required by CRANE (the national cleft database), the Quality Dashboard and the Tri/Quad centre audit groups.

Service model and Care Pathway

Providers will work with clinical and commissioning colleagues to provide integrated services through managed clinical networks across the patient pathway.

The service will work as a 'Hub and Spoke' model with all cleft surgery taking place at the specialist centres (Hub) and all core disciplines being centred at and directed from the Hub, notwithstanding that some centres are twin site. Some centres will have no choice but to have separate hubs for child and adult services but the service will be delivered by the same team.

Services may be delivered by Hub clinicians in the centre or by outreach but may be

delivered by local specialist clinicians working as prescribed by hub clinicians, for example in SLT, dentistry, orthodontics, ENT/Audiology. Those services for cleft related care in those specialities/disciplines will be prescribed and coordinated by the Hub for local delivery of the clinical pathway in a timely and appropriate manner. These pathways are based on national policy, guidelines and best practice. Such therapy should be delivered according to prescription for as long as considered necessary in the prescription and within a timely fashion (no more than 18 week wait).

The service will strive to contribute to clinical research and when possible basic research into aetiology of cleft lip and / or palate and the best means of treating the conditions. In particular the service will aim to collaborate with the Cleft Collective and National Institute for Health Research (NIHR) funded studies.

The service will also strive to develop innovation in care delivery whenever possible and share these with the wider cleft care community.

The care pathway diagram for CLP is shown overleaf. The precise pathway will vary with the cleft diagnosis, dependent to some extent on co-morbidity, geography and the way in which local and centre services are delivered.

The service elements in the CLP pathway are listed under 3.2 on pages 5 and 6 of this document.

General Paediatric care

When treating children, the Service will additionally follow the standards and criteria outlined in the Specification for Children's Services (attached as Annex 1, Page 26 of this Specification).

Principles of care

To provide a safe, cost effective, high quality specialised service for people with Cleft Lip and/or Palate to improve their quality of life by:

- Providing a personal service, sensitive to the physical, psychological, intellectual and developmental needs of the patients and their family/carers
- Ensuring equity of access to services for those with Cleft Lip and/or Palate taking into account a patient's location and the distance they travel
- Offering informed choice to people with Cleft Lip and/or Palate
- Ensuring an appropriate transition to adult care
- Ensuring effective communication and support between patients, their family/carers and the service providers
- Ensuring the Service has a formal appointment policy and follow-up process in case of non-attendance
- The Service should have a clear written policy for children who do not attend 2 successive appointments in order to ensure that no child is disadvantaged. This should be based on a team discussion, agreement on action which may include a

letter or direct approach to parents/carers and if this does not resolve the situation may require referral to social agencies. In all such cases the paramount interests of the child must be placed first. In principle, no child will be discharged from the service for non-attendance or non-compliance with treatment in order to ensure that children are not disadvantaged.

- Since service delivery in some disciplines (e.g. speech and language therapy) is often delivered locally, the commissioners will ensure that the lead provider/cleft centre has the means to ensure such delivery to the service standards and to cleft centre prescription whether the service is funded locally or centrally
- None of the services listed in this service specification will be subject to prior approval whether for children or adults

Clinical responsibility

- The provider is responsible for all risks arising in connection with the provision of the services (whether arising directly or indirectly) under the terms of this specification.
- All patients who are treated by the provider, whether in the main Cleft Lip and Palate centre or in local or community facilities, shall remain under the overall clinical CLP care of the hub. This includes outreach facilities, whether or not they are directly subcontracted.
- Clinical management of eligible patients will be in line with the agreed care pathway and any relevant regulations governing delivery of services.
- The provider will coordinate any associated in-patient, day care and out-patient services to ensure continuity of care. Specialist Cleft Lip and Palate staff, equipment and care will be available irrespective of the care setting, for patients with Cleft Lip and/or Palate admitted to hospital.

Service requirements

A proportion of patients with Cleft Lip and/or Palate conditions may have single or multiple medical/congenital conditions and treatment may need to be developed in conjunction with other clinical priorities.

Service configuration

The Cleft Lip and Palate service will operate via a managed clinical network. This national service specification and the DH document HSC 1998/238 (Appendix 3) describes key responsibilities and skill mix of the main team, led by a clinical director with supporting care co-ordinator/manager, and each Regional Centre/MCN treating a minimum of 80 – 100 new cleft births per year. Updated details on this can be found in the next section/s of this document.

Workforce requirements

It is recognised that patients with Cleft Lip and/or Palate have complex medical, emotional and social needs. Access to a broad range of professionals is essential for delivering optimum and timely therapy. The provider will have sufficient clinical and support staff in line with *DH HSC 1998/238* requirements (see Appendix 3). The Care Pathway and the Multi-Disciplinary Team are based on this circular but after 14 years of re-organised cleft care in the UK, some recommendations have been changed or modified to achieve better outcomes.

The Multi-disciplinary Team (most of whom will be based at the Cleft centre/hub)
Clinical Director , responsible for the service and to ensure that each discipline has sufficient staff to provide the service and to maintain high standards and skills
Care Co-ordinator
Service Manager
Lead Cleft Surgeons , who will devote a majority of their clinical time to cleft care and will work within the multi-disciplinary team, bearing in mind the team's need to manage succession planning. Surgeons undertaking primary lip and palate repair should be treating not less than 30 new babies per year notwithstanding the aim in HSC 1998 238 for 40-50 new babies per year per surgeon. New surgeons shall have met the requirements of a Training Interface Groups (TIG) approved cleft surgery fellowship training or equivalent.
Lead Paediatric Anaesthetist , with a special interest in cleft care
Lead Specialist in Paediatric Dentistry , with a special interest in cleft care
Lead Consultant Orthodontist , with major commitment to cleft care
Lead Specialist Speech and Language Therapist , with major commitment to cleft care
Lead Consultant Paediatrician/s , ensuring good paediatric surveillance and on-going paediatric care
Lead Consultant ENT surgeon , with pediatric otology experience and/or Audiological Physician , with an interest in children's hearing.
Lead Clinical Nurse Specialist
Lead Clinical Psychologist (preferably a Consultant Clinical Psychologist)
Lead Consultant Restorative Dentist
Lead Consultant Clinical Geneticist

Each lead clinician will have such additional staff in their discipline/specialty as are needed to provide the service.

Each cleft team will facilitate/encourage user involvement by including (a minimum of 2) patient representative(s) in their service development and review processes and meetings.

The hub team will require the support of clinical photography, dedicated Information Technology (IT) support especially for archiving of records and to support general team activity, radiologists and radiographers, maxillofacial and orthodontic technicians, secretarial and clerical staff, and audit support staff. The extended team will include local speech and language therapists, audiologists, orthodontists, local and community paediatricians, geneticists and ENT surgeons. There will also be close liaison with ultrasound diagnosticians and foetal medicine experts.

Other services to be provided

Patient education: The provider will offer all patients, together with their family and carers, appropriate opportunities to learn more about their diagnosis and prognosis and the treatment options available to them. In some cases, more formal education may be offered which might include members from the multi-professional team who can provide a wider range of information according to the individual patient's needs, e.g. dental care, speech development, eating and drinking skills.

The provider will offer appropriate printed information covering advice, treatment and care to patients, general practitioners and patient groups that is non-discriminatory and culturally appropriate. The information should also be accessible to patients with additional needs such as physical, sensory or learning disabilities. Providers should also make patients aware of other sources of information, including appropriate websites and local/national support groups.

The CNS in the Cleft team will offer printed information and training to maternity services in their area to promote early identification and referral.

Patient support groups: The provider should ensure that patients and carers are provided with information about local and national support groups and how to access them, as it is recognised that these are a vital source of peer support, advice and information for patients. Signposting information will be displayed within the provider's facilities.

Clinical Governance

The provider will provide and ensure that all staff adheres to its policies, procedures, and clinical guidelines as agreed with commissioners.

Every patient must have a named consultant responsible for their care.

A member of the team will be offered as a keyworker to support families throughout the clinical pathway if required.

Radiology systems

The provider will ensure full access to the radiology picture archiving and communication system (PACS) of the hospital where most radiology investigations are undertaken.

PAS / HISS systems

The provider will ensure full access to its Health Informatics Services (HISS) computing system or Patient Administration System (PAS).

Service monitoring meetings

The provider will meet with the service commissioner on an annual basis at a minimum to review the service utilisation and improve on any aspects of the service as required. A representative of service users will be invited to this meeting.

Information regarding treatment options

The provider shall provide information, advice and support for a range of treatment options as set out in section 3.2 – service model. The provider will ensure patients receive a copy of all appropriate correspondence regarding their care.

On-call cover

In-patients and emergency out-patients will be covered routinely round the clock 365/6 days a year mostly by the cleft team but some surgical on-call cover may need to be provided within the surgeon's parent speciality and this should be formalised.

Response time and detail and prioritisation

The provider will ensure that all services are delivered in a timely manner and in accordance with national standards. Treatment will be prioritised according to clinical need and where clinical need is the same, through chronological waiting list management provided this does not contravene agreed treatment protocols. Any diagnostic tests and investigations will be completed within 6 weeks in accordance with the NHS constitution.

* Note: for the purposes of commissioning health services, this EXCLUDES patients who, whilst resident in England, are registered with a General Practitioner (GP) Practice in Wales, but INCLUDES patients resident in Wales who are registered with a GP practice in England.

Specifically, this service is for patients of all ages with Cleft Lip and/or Palate

including non-cleft Velopharyngeal Dysfunction (VPD) requiring specialised intervention and management, as outlined within this specification.

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)

3.4 Any acceptance and exclusion criteria and thresholds

Acceptance criteria

The service will accept inward referrals from primary, secondary, tertiary and community care clinicians.

The service will accept referrals for patients who meet one of the following criteria:

- Patients with Cleft Lip and/or Palate (CLP)
- Patients with non-cleft Velopharyngeal Dysfunction (VPD)
- Expectant mothers with a prenatal diagnosis of a baby with CLP.

Referrals will be handled by the receiving service according to the decisions made by the clinical director in conjunction with the multidisciplinary team.

The point at which a patient with Cleft Lip and/or Palate requires treatment is a shared decision between the patient and their family/carer and their clinician. There are no specific exclusion criteria that apply to this service.

3.5 Interdependencies with other services/providers

Co-located services

Services that need to be provided on the same site as CLP surgery are:

- Paediatric ENT airway support or appropriate protocols for paediatric airway support
- Paediatric Critical Care, generally high dependency but in some cases access to Paediatric intensive care (PICU) will be required. In general access to or written protocols for retrieval to PICU will be required.
- Specialised Paediatric Anaesthesia.

The Cleft core MDT will be based at the surgical centre (see 2.2.6) however some team members do not have an absolute requirement to be based at the centre - see (ii).

Interdependent services

Members of the multidisciplinary team (MDT) who do not need to be based at the centre but need to be readily available are:

- Restorative dentistry
- Genetics

Patients with Cleft Lip and/or Palate often also have other medical conditions, particularly congenital cardiac anomalies, other craniofacial anomalies etc. It is therefore essential that strong clinical linkages are made with service areas managing those co-morbidities.

Related services

The service described in this specification relies on local Clinical Commissioning Group (CCG)/local authority commissioned services to deliver some elements of the CLP pathway. The services described in Appendix 2 will often be commissioned at a local level to support the nationally commissioned CLP services. Those local services are integral to the service and commissioning must be seamless so that there is no disruption to full delivery of the entire care pathway as prescribed by the hub CLP team.

- Local Paediatric Services eg. Health visitors, School nurses, SLT, Dentists, Audiology/Hearing services
- General Practitioners, General Dental Practitioners and community services
- Secondary and Tertiary provider clinicians and specialist nurses
- Patient Transport Services

Essential Service Linkages with Cleft Lip and Palate Services

	Specialised Services for Children (SSNDS No.23)	
NHS Non Specialised healthcare Patient's GP Patient's GDP Paediatric inpatient facilities inc. anaesthetic services, play therapists Community Paediatricians Community SLT Local Mental Health Services	Cleft Lip and Palate Service SSNDS	Non NHS Services Local Education/social Care Services Children's Centres Support groups Charitable organisations Service User representatives
	Medical Genetics	

Facilities and Equipment

Facilities

- Access to High Dependency Units (HDU)/Paediatric Intensive Care Units
- Access to paediatric surgical area including recovery area
- Dental clinics which facilitate orthodontics and paediatric dental services
- Computer support which facilitates web based data entry for submission to the CRANE database and Quality Dashboard
- Appropriate facilities for multidisciplinary clinics (number and kind of rooms, play areas, waiting areas) and facilities must at least meet paediatric NSF standards.

Equipment

- Appropriate imaging equipment to facilitate the management and assessment of outcome of skeletal (including orthognathic) surgery and orthodontic treatment
- Appropriate quality dental x-ray facilities meeting national standards
- Access to videofluoroscopy
- Equipment for nasendoscopy
- Operating microscope

4. Applicable Service Standards

4.1 Applicable national standards e.g. NICE

Core Standards are those which all cleft centres will meet during the contractual year 2013/14)

Recommended Standards are those which some centres may not be able to meet in 2013/14 but will be expected to meet as soon as possible after that year following discussions if necessary with commissioners

Antenatal Care Standards

Core Standards

1.	Parents will be contacted by a cleft team Clinical Nurse Specialist within 24 hours of receiving the referral.
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2.	Parents will be offered a visit from a CNS at an appropriate and negotiated time and place.
3.	A record will be kept by the cleft team of the outcome of the pregnancy (including, as appropriate, cleft type) for all antenatal referrals.

Recommended Standards

4.	The regional team will agree protocols with, and provide information to, each unit in its region that carries out 20 week scans to maximise the diagnosis of cleft lip, and to ensure that on the day of initial diagnosis: (a) parents are referred by relevant professionals to the cleft team; and (b) parents are given printed information provided by the cleft team
5.	The Clinical Nurse Specialist will make contact with the primary health care team during the antenatal period In the antenatal period following a diagnosis, all parents will be offered: <ul style="list-style-type: none"> • An appointment with the cleft team • Counselling and support • Appropriate feeding preparation and plan for immediate postnatal period • Verbal and written information re cleft treatment and management • Contact with a family of a child with a similar diagnosis (ideally a trained CLAPA parent contact with a similar diagnosis if available) • Written information about CLAPA

Post Natal & Infant Care Standards

Core Standards

6.	A Clinical Nurse Specialist should visit the mother and baby within 24 hours of receiving the referral.
8.	A feeding plan should be devised and documented which supports the mother's preference for feeding at the first visit.
9.	All babies should have a nationally-recognised feeding assessment prior to the introduction of assisted feeding.

10.	All parents to be offered: <ul style="list-style-type: none"> • Counselling and support • Verbal and written information re cleft treatment and management • Contact with a family of a child with a similar diagnosis (ideally a trained • CLAPA parent contact with a similar diagnosis if available) • Written information about CLAPA
11.	All parents will be offered the opportunity of visiting the ward at the surgical centre prior to any surgery being undertaken
12.	Parental consent will be sought to register the details of the baby onto CRANE (Craniofacial Anomalies Register), and to hold data on the baby and his/her parents on local cleft databases.

Recommended Standards

13.	An electric breast pump should be offered to all mothers who need one, for as long as they need it, without charge.
14.	A Clinical Nurse Specialist shall visit all babies at home within one week of discharge
15.	Arrangements must be in place to monitor parental satisfaction with the early care of the child and the effectiveness of the initial interventions, for example through a validated satisfaction questionnaire.

Additional Recommended Standards for Maternity Services

16.	All babies born with Cleft Lip and/or Palate should be diagnosed by birth.
17.	All babies are to be referred by relevant professionals to the cleft team within 24 hours of diagnosis.

Care and Facilities for Children & Young People Standards

Core Standards

18.	All babies with clefts will be fully assessed clinically by a Paediatrician for the presence of other congenital malformations and investigated further if required
19.	All children and young people receiving cleft care should be treated in an appropriate paediatric environment, the general features of which are set out in the National Service Framework for Children 2003
20.	All families of children with a cleft will be offered assessment by and will have access to support from a member of the Cleft Clinical Psychology team before the first operation is carried out.

Additional Recommended Standards for Paediatric Services

21.	Babies and children with cleft involvement will have regular, local, paediatric follow up to ensure appropriate growth and development, especially in the first 24 months of life.
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Cleft Surgery Standards

Core Standards

22.	Cleft surgeons must have appropriate experience and training and a proven commitment to cleft care. They will devote a majority of their clinical time to cleft care and will work within the multi-disciplinary team, bearing in mind the team's need to manage succession planning.
23.	Surgeons undertaking primary lip and palate repair should be treating not less than 30 new babies per year notwithstanding the aim in HSC 1998 238 for 40-50 new babies per year per surgeon. The number of new babies treated over a period (e.g. 3 years) will be considered. New surgeons shall have met the requirements of a TIG approved cleft surgery fellowship training or equivalent.
24.	With regard to cleft surgery in general and the need to devote a majority of their clinical time to cleft care, the surgeon's experience, historical numbers treated, past audited performance / outcomes, other cleft surgery performed e.g. secondary surgery, ABGs, orthognathic surgery, speech surgery, and revisions, will be considered.
25.	All cleft surgeon(s) will participate in audit and will aim to achieve good outcomes in terms of the appearance of lip repair, as well as lip function, and palatal function as demonstrated by speech and good growth outcomes as well as quality of outcome in all aspects of cleft surgery including ABG, orthognathic, implants, speech and revisional surgery.
26.	The cleft surgeon(s) must adhere to a strict protocol as part of an integrated care pathway of surgical care as previously agreed by the centre, notwithstanding the need from time to time to vary that protocol to deal with unusual clinical situations. No variation from the general protocol will be acceptable unless agreed by the team as a result of evidence based audit / research.
27.	All clefts involving the alveolus (including isolated cleft lip which may involve the alveolus) will be assessed before the age of 9 years by a cleft team orthodontist in conjunction with a cleft surgeon responsible for alveolar bone grafting. The assessment will be carried out in a multidisciplinary clinic, involving a paediatric dentist where appropriate, and will determine the need for, preparation for and timing of the alveolar bone grafting procedure.
28.	All clefts involving the alveolus will be grafted by the age of 12 years provided that it is done before the eruption of the permanent maxillary canine tooth on the cleft side unless there is a specific reason e.g. medical

considerations, very delayed dental development or hypodontia, patient refusal or non-compliance.

ENT & Audiology Services Standards

Core Standards

29.	All children with a cleft palate should have their hearing assessed by a clinician trained in paediatric audiology before the gestational age of 10 months (in addition to the national newborn hearing screen within the first few days of life). They should receive follow-up audiological care and appropriate audiometric assessments, not less frequently than once a year for the first 3 years, again at school entry and at 5 years and 10 years of age. NB: In some cases follow up care may be provided by non prescribed, locally commissioned ENT and Audiology services.
30.	All families of children with cleft palate should receive information about the risks of hearing loss and how to look out for it before the child is 10 months old.
31.	All children with persistent conductive hearing loss must receive careful review by a clinician expert in otoscopy.

Speech & Language Therapy Standards

Core Standards

32.	For patients 5 – 11 years of age each centre will collate data as laid down by the Lead SLT Group in order to strive to achieve the National Standards for Speech for children with cleft palate (+/- cleft lip/alveolus) relating to process (10.4–10.7) and outcome (10.8–10.12) (see Appendix 4)
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Recommended standards

33.	For patients 10 – 11 years of age each centre will collate data as laid down by the Lead SLT Group in order to strive to achieve the National Standards for Speech for children with cleft palate (+/- cleft lip/alveolus) relating to process (10.4–10.7) and outcome (10.8–10.12) (see Appendix 4)
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Dental Health Standards

Core Standards

34.	All children born with a cleft lip and/or palate will receive preventive
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	dental advice and support by the time the child is six months of age and will have treatment if needed arranged or provided to aim to ensure that their level of dental disease is the same as or better than the average in their local community.
35.	All children born with a cleft lip and/or palate will receive treatment as needed to maintain optimum dental health. Where possible treatment will be provided locally but all patients should have access to advice and treatment by the lead specialist in paediatric dentistry dependent on the level of care needed.
36.	<ol style="list-style-type: none"> 1. All children with missing or abnormally formed teeth will be assessed by a specialist in paediatric dentistry before the age of 10 years, the aim being to determine the degree of dental abnormality and provide protection of defects to prevent further deterioration and for aesthetic improvement if indicated prior to change to high school. 2. Planning and provision of longer term restorative solutions should be undertaken in conjunction with the team orthodontist by either a paediatric dental or restorative dental consultant (implants to be provided if clinically indicated by the restorative dental team after completion of growth) by age 15 years, although it is recognized that later assessments for adults and treatment will be required in some if not many cases.

Recommended Standard

37.	For children who have completed orthodontic treatment the Peer Assessment Rating (PAR) score should be applied to start and finish of treatment models. The change in PAR scores should relate favourably to any established National Standards.
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Clinical Psychological & Counselling Services Standards

Core Standard

38.	All parents and children with clefts will be regularly assessed and offered psychological support if needed.
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Recommended Standard

39.	The Lead Clinical Psychologist will ensure that all children with cleft lip and/or palate have audit records collected in line with national audit recommendations. National and international comparisons will be made and the service will meet any clinical need identified including clinical psychology therapy sessions.
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Genetic Services Standard

Core Standard

40.	All patients (and their parents) will be offered a referral to the Clinical Genetics service when appropriate and at discharge from the Cleft team.
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Audit Records and Post-Infant Patient/Parent Satisfaction

Recommended Standard

41.	The standard record set should be available, or else the reason for non-collection recorded, for 100% of all cleft individuals at each age band. Patient and Parent satisfaction questionnaires will be used to assess the team's performance in adolescence and at the end of routine care
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Adults Returning to the Service

Core Standard

42.	Any adult who has missed out on the care pathway should be assessed and treated according to the Clinical Service Specification in so far as that is clinically possible and appropriate regardless of age, according to clinical need and in an appropriate environment.
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4.2 Applicable standards set out in Guidance and/or issued by a competent body (e.g. Royal Colleges)

- Professional bodies with an interest and national guidance:
- National UK NHS Cleft Development Group
- Craniofacial Society of Great Britain and Ireland
- Craniofacial Anomalies Register (CRANE Database)
- Cleft Lip and Palate Association (CLAPA)
- National and local health service bodies and relevant local Government authorities
- National Institute for Clinical Excellence (NICE)
- NHS Employment Check Standards
- CNST General Clinical Risk management standard appropriate to the service being delivered;
- Health Building Note (HBN) 07-01 / 07-02
- Royal College of Surgeons Clinical Standards
- Royal College of Speech Therapy, Communicating Quality 3 2006
- British Association of Oral and Maxillofacial Surgeons
- British Association of Plastic, Reconstructive and Aesthetic Surgeons

- British Association of Orthodontists
- Cleft Special Interest Groups (SIGs)

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)

There is no national CQUIN for this service

6. Location of Provider Premises

The Provider's Premises are located at:

Name of Cleft Centre	Cleft Sites
Northern and Yorkshire	Royal Victoria Infirmary, Newcastle upon Tyne Hospitals NHS Foundation Trust Leeds General Infirmary, Leeds Teaching Hospitals NHS Trust
The North West, Isle of Man and North Wales* Regional Network	Royal Manchester Children's Hospital, Central Manchester University Hospitals NHS Foundation Trust University Hospital Of South Manchester NHS Foundation Trust Alder Hey Children's NHS Foundation Trust Aintree University Hospital NHS Foundation Trust
Trent	Queen's Medical Centre Campus, City Campus Nottingham University Hospitals NHS Trust
West Midlands	Birmingham Children's Hospital NHS Foundation Trust The new Queen Elizabeth Hospital,

	University Hospitals Birmingham NHS Foundation Trust
Cleft.Net.East	Addenbrooke's Hospital, Cambridge
	Cambridge University Hospitals NHS Foundation Trust
North Thames	Great Ormond Street Hospital for Children NHS Trust, London
	St Andrew's Centre, Broomfield Hospital, Chelmsford
The Spires	John Radcliffe Hospital, The Oxford University Hospitals NHS Trust
	Salisbury District Hospital, Salisbury NHS Foundation Trust
South Wales* and South West MCN	<i>Morrison Hospital, Swansea, ABM University Health Board</i>
	Frenchay Hospital, North Bristol NHS Trust
South Thames	Guy's Hospital, London. The Evelina Children's Hospital.
	Guy's and St Thomas' NHS Foundation Trust

7. Individual Service User Placement

Care Pathway for CLP

Banding as 0-2 years, 3-7 years, 8-14 years, 15-21+ years

	Ante-natal	Birth to 8 wks	9 wks - 2 yrs	3 - 7 years	8 years – 14 years	15 – 21+ years	> 21 yrs returning
Local Obstetric Units	<ul style="list-style-type: none"> • Ultrasound scan diagnosis, confirmed if necessary by foetal medicine specialist • Local obstetric unit to contact Cleft Team within 24 hours of diagnosis 	<ul style="list-style-type: none"> • Local maternity unit to contact Cleft Team within 24 hours of birth 					
Main 'Hub' Cleft Centres (including MDT clinics organised by the Hub at Spokes)	<ul style="list-style-type: none"> • Contact by Cleft Clinical Nurse Specialist (CNS) within 24 hours of referral. • Provide printed 	<ul style="list-style-type: none"> • CNS visit within 24 hrs of referral • Specialist feeding assessment and management, printed information, offer 	<ul style="list-style-type: none"> • Lip repair at 3-6 months • Palate repair 6-12 months • Refer for local ENT assessment and management 	<ul style="list-style-type: none"> • Psychological support prior to school entry • Surgery to revise lip and speech (velo-pharyngeal) surgery if necessary, these to be available if 	<ul style="list-style-type: none"> • Assessment between 7 years of age and before 9 years by Cleft team Orthodontist , Paediatric Dentist and Surgeon 	<ul style="list-style-type: none"> • Definitive orthodontic care • Full MDT clinic and records at 15 and 20 years • Offer Genetic referral 	<p>Continuation of/or return to care from previous period</p> <p>Adult patients returning for care may require</p> <ul style="list-style-type: none"> • Speech and

	Ante-natal	Birth to 8 wks	9 wks - 2 yrs	3 - 7 years	8 years – 14 years	15 – 21+ years	> 21 yrs returning
	<p>information</p> <ul style="list-style-type: none"> • Negotiate face to face meeting • offer contact with CLAPA 	<p>Cleft Lip And Palate Association (CLAPA) referral</p> <ul style="list-style-type: none"> • Meet Cleft team and/or Multi-disciplinary Team (MDT) Baby clinic before any cleft surgery • Ensure appropriate Paediatric surveillance for co- morbidity & syndromes • Clinical Psychology support offered at all team clinics and available throughout all the time points in the care pathway 	<p>if cleft palate</p> <ul style="list-style-type: none"> • Speech and language assessment usually at 18 months, and management • Paediatric dentist for dental health education/ advice by 6 months of age and direction / liaison with appropriate general dental care • Later investigation (e.g. nasendoscopy and videofluoroscopy) for speech problems if necessary and this may be required at any stage in the care pathway 	<p>needed throughout the care pathway</p> <ul style="list-style-type: none"> • Full MDT and records at 5 years • Paediatric Dentistry advice and/or intervention if necessary 	<p>responsible for ABG, if an alveolar defect is present</p> <ul style="list-style-type: none"> • Paediatric Dentistry and Orthodontic treatment • If required, pre-ABG orthodontic care followed by Alveolar Bone Grafting completed before 12 years – follow-up at 6 months post-op • Full MDT and records at 10 years • Speech and Hearing checked and managed if palatal involvement • Definitive 	<ul style="list-style-type: none"> • Team assessment for Orthognathic surgery if indicated • Planning and pre-treatment for skeletal surgery • Orthognathic surgery and associated Orthodontics if indicated • Revisional surgery if indicated (nose, lip) • Paediatric to Restorative Dentistry as indicated • Completion of Post-Orthognathic surgery records and Speech assessment • Speech revision 	<p>Language assessment and therapy</p> <ul style="list-style-type: none"> • Lip and/or Nose revisional surgery • Speech revision surgery • Palatal fistula repair • Orthodontics • ABG if not done previously • Orthognathic surgery • Clinical Psychology • Hearing assessment and treatment • Restorative

	Ante-natal	Birth to 8 wks	9 wks - 2 yrs	3 - 7 years	8 years – 14 years	15 – 21+ years	> 21 yrs returning
		<ul style="list-style-type: none"> Genetics referral if indicated 			<ul style="list-style-type: none"> Orthodontic care Paediatric Dentistry if necessary 	<ul style="list-style-type: none"> surgery if indicated 	<ul style="list-style-type: none"> dentistry
Local Care		<ul style="list-style-type: none"> Paediatric surveillance for co-morbidity & syndromes Neo-Natal Hearing Test within first few days after birth for ALL babies Genetic counselling to parents if indicated 	<ul style="list-style-type: none"> 10 months hearing test if cleft palate and treatment as necessary Annual hearing assessments up to 3 years of age if cleft palate Speech and language therapy assessment 	<ul style="list-style-type: none"> Later Speech and language therapy ENT and audiology assessment if cleft palate at 3 years of age, pre-school entry and 5 years of age (5 years of age assessment may be local or at Cleft Team 5 year MDT) 	<ul style="list-style-type: none"> Speech and hearing problems managed Local Orthodontics 	<ul style="list-style-type: none"> Continuing orthodontic treatment-paediatric and restorative dental care in close liaison with 'centre' 	
Primary Care		<ul style="list-style-type: none"> Dental health education in liaison with main centre 	<ul style="list-style-type: none"> Dental health education in liaison with main centre Routine child health surveillance 	<ul style="list-style-type: none"> Routine preventative dental advice and treatment 	<ul style="list-style-type: none"> Routine preventative dental advice and treatment 	<ul style="list-style-type: none"> Regular dental care 	<ul style="list-style-type: none"> Regular dental care

“Full multidisciplinary team” is Cleft surgeons, Lead Orthodontist, Lead Paediatric Dentist, Clinical Psychologist (preferably a Consultant Clinical Psychologist), Speech and Language Therapist/s, Lead for ENT/Audiology and may also include Consultant in Restorative Dentistry, local Orthodontists, local Speech and Language Therapists, Paediatrician and Paediatric Anaesthetist, Nurses and Coordinator

Patients attend a clinic as locally as possible. Photographic facilities are required at all clinics and for pre- and post-op photographs.

Children and/or parents can be referred to Genetics at any time during their care. Specialist nurses will carry out regular home visits as necessary until after all primary surgery has been completed.

Appendix Two

Appendix One

Quality standards/outcomes specific to the service using the following template:

N/A

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
Domain 1: Preventing people dying prematurely			
Domain 2: Enhancing the quality of life of people with long-term conditions			
Families are supported by the CLP Clinical Nurse specialist (CNS) at an early stage following diagnosis.	100%	Dashboard	As per Standard NHS Contract, General Conditions Clause 9 (GC9) Remedial Action Plan
All babies with CLP receive initial lip and palate surgery at the optimal time to achieve best results.	Number of babies receiving first lip repair by 6 months of age, in the absence of specific clinical reasons for delay Number of babies receiving first palate repair by 13 months in the absence of specific clinical reasons for delay	Dashboard	As per Standard NHS Contract, General Conditions Clause 9 (GC9) Remedial Action Plan
5 year old children with CLP will have had hearing issues addressed.	100%	Dashboard	As per Standard NHS Contract, General Conditions Clause 9 (GC9) Remedial Action Plan
All children with CLP at 5 years of age will have dental health which is at least as good as that of children without CLP in their region.	100%	Dashboard	As per Standard NHS Contract, General Conditions Clause 9 (GC9) Remedial Action Plan
Children with CLP achieve good quality, intelligible speech between the age of 5 and 6 years.	100%	Dashboard	As per Standard NHS Contract, General Conditions Clause 9 (GC9) Remedial Action Plan
Children with UCLP have good maxillary growth and achieve good facial appearance	The 5 year Olds' Index as indicator of maxillary growth in patients with complete UCLP	Dashboard	As per Standard NHS Contract, General Conditions Clause 9 (GC9) Remedial Action Plan

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
All children requiring alveolar bone grafting will receive that treatment at optimum times and with good results	100%	Dashboard	As per Standard NHS Contract, General Conditions Clause 9 (GC9) Remedial Action Plan
All children with CLP will have acceptable appearance in their permanent dentition	100%	Dashboard	As per Standard NHS Contract, General Conditions Clause 9 (GC9) Remedial Action Plan
Domain 3: Helping people to recover from episodes of ill-health or following injury			
Domain 4: Ensuring that people have a positive experience of care			
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm			

Appendix Two: Glossary

CLAPA	Cleft Lip and Palate Association, a parent / patient group
CRANE	Craniofacial Anomalies Register, national cleft database
CSAG	Clinical Standards Advisory Group, NHS body which investigated cleft care and reported in 1998
CRG for CLP	NHS England Clinical Reference Group for Cleft Lip and/or Palate specialist services
CDG	National UK Cleft Development Group responsible for oversight of cleft care in the UK and for the national cleft database, CRANE
CFSGBI	Craniofacial Society of Great Britain and Ireland, the society representing professionals working in the field of cleft and craniofacial care
Cleft Collective	UK Research initiative developed by a charity, The Healing Foundation, to carry out clinical trials in the field of cleft care and a gene bank
dmft score	Decayed, missing, filled and treated deciduous teeth score
DMFT score	Same for permanent teeth
GOSLON	Dental model score as an indicator of maxillary (upper

score/yardstick	jaw) growth – age 12 yrs
5 Year Index	Same age 5 yrs
PAR Score (*)	Peer Assessment Rating of Orthodontic treatment
Alveolus	The bone of the jaws in which the teeth develop and the erupted tooth roots can be found. This bone supports the teeth.
ABG	Alveolar cleft bone graft. Insertion of bone graft into gap in the alveolar bone where the cleft is
TIG	Cleft Surgery Training Interface Group, the multi-surgical specialty group which arranges and supervises cleft surgery fellowships in the UK
Distraction Osteogenesis	Gradual bone lengthening
Osteotomy	Immediate bone lengthening, shortening or movement by creating a fracture
Otology, Otolaryngology, Otorhinolaryngology	ENT
Otoscopy (*)	Examination of the ear
Rhinoplasty	Re-shaping of the nose
22q11 deletion	An abnormality (deletion) of chromosome 22q11
Velopharyngeal Dysfunction (VPD)	Abnormality of nasal speech (resonance) due to failure of normal function of the sphincter between the soft palate and the pharynx (back of the throat)

ANNEX 1 TO SERVICE SPECIFICATION:

PROVISION OF SERVICES TO CHILDREN

Aims and objectives of service

This specification annex applies to all children's services and outlines generic standards and outcomes that would be fundamental to all services.

The generic aspects of care:

The Care of Children in Hospital (HSC 1998/238) requires that:

- Children are admitted to hospital only if the care they require cannot be as well provided at home, in a day clinic or on a day basis in hospital.
- Children requiring admission to hospital are provided with a high standard of medical, nursing and therapeutic care to facilitate speedy recovery and minimize complications and mortality.
- Families with children have easy access to hospital facilities for children without needing to travel significantly further than to other similar amenities.
- Children are discharged from hospital as soon as socially and clinically appropriate and full support provided for subsequent home or day care.
- Good child health care is shared with parents/carers and they are closely involved in the care of their children at all times unless, exceptionally, this is not in the best interest of the child; Accommodation is provided for them to remain with their children overnight if they so wish.

Service description/care pathway

- All paediatric specialised services have a component of primary, secondary, tertiary and even quaternary elements.
- The efficient and effective delivery of services requires children to receive their care as close to home as possible dependent on the phase of their disease.
- Services should therefore be organised and delivered through "integrated pathways of care" (*National Service Framework for children, young people and maternity services* (Department of Health & 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 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 for the Provision of Anaesthetic Services (GPAS) Paediatric anaesthetic services. Royal College of Anaesthetists (RCoA) 2010
www.rcoa.ac.uk

2. Certificate of Completion of Training (CCT) in Anaesthesia 2010
3. CPD matrix level 3

Specialised Child and Adolescent Mental Health Services (CAMHS)

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

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

- Facilities and environment – essential Quality Network for In-patient CAMHS (QNIC) standards should apply (<http://www.rcpsych.ac.uk/quality/quality,accreditationaudit/qnic1.aspx>)
- Staffing profiles and training - essential QNIC standards should apply.
- The child/ young person's family are allowed to visit at any time of day taking account of the child / young persons need to participate in therapeutic activities and education as well as any safeguarding concerns.
- Children and young people are offered appropriate education from the point of admission.
- Parents/carers are involved in the child/young persons care except where this is not in the best interests of the child / young person and in the case of young people who have the capacity to make their own decisions is subject to their consent.
- Parents/carers who wish to stay overnight are provided with accessible accommodation unless there are safeguarding concerns or this is not in the best interests of the child/ young person.

Applicable national standards e.g. NICE, Royal College

Children and young people must receive care, treatment and support by staff registered by the Nursing and Midwifery Council on the parts of their register that permit a nurse to work with children (Outcome 14h Essential Standards of Quality and Safety, Care Quality Commission, London 2010)

- There must be at least two Registered Children's Nurses (RCNs) on duty 24 hours a day in all hospital children's departments and wards.
- There must be an Registered Children's Nurse available 24 hours a day to advise on the nursing of children in other departments (this post is included in the staff establishment of 2RCNs in total).

Accommodation, facilities and staffing must be appropriate to the needs of children and separate from those provided for adults. All facilities for children and young people must comply with the Hospital Build Notes *HBN 23 Hospital Accommodation for Children and Young People* NHS Estates, The Stationary Office 2004.

All staff who work with children and young people must be appropriately trained to provide care, treatment and support for children, including Children's Workforce Development Council Induction standards (Outcome 14b *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010).

Each hospital who admits inpatients must have appropriate medical cover at all times taking account of guidance from relevant expert or professional bodies (National Minimum Standards for Providers of Independent Healthcare, Department of Health, London 2002). "*Facing the Future*" Standards, Royal College of Paediatrics and Child Health.

Staff must carry out sufficient levels of activity to maintain their competence in caring for children and young people, including in relation to specific anaesthetic and surgical procedures for children, taking account of guidance from relevant expert or professional bodies (Outcome 14g *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010).

Providers must have systems in place to gain and review consent from people who use services, and act on them (Outcome 2a *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010). These must include specific arrangements for seeking valid consent from children while respecting their human rights and confidentiality and ensure that where the person using the service lacks capacity, best interest meetings are held with people who know and understand the person using the service. Staff should be able to show that they know how to take appropriate consent from children, young people and those with learning disabilities (Outcome 2b) (*Seeking Consent: working with children* Department of Health, London 2001).

Children and young people must only receive a service from a provider who takes steps to prevent abuse and does not tolerate any abusive practice should it occur (Outcome 7 *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010 defines the standards and evidence required from providers in this regard). Providers minimise the risk and likelihood of abuse occurring by:

- Ensuring that staff and people who use services understand the aspects of the safeguarding processes that are relevant to them.
- Ensuring that staff understand the signs of abuse and raise this with the right person when those signs are noticed.
- Ensuring that people who use services are aware of how to raise concerns of abuse.
- Having effective means to monitor and review incidents, concerns and complaints that have the potential to become an abuse or safeguarding concern.

- Having effective means of receiving and acting upon feedback from people who use services and any other person.
- Taking action immediately to ensure that any abuse identified is stopped and suspected abuse is addressed by:
 - having clear procedures followed in practice, monitored and reviewed that take account of relevant legislation and guidance for the management of alleged abuse
 - separating the alleged abuser from the person who uses services and others who may be at risk or managing the risk by removing the opportunity for abuse to occur, where this is within the control of the provider
 - reporting the alleged abuse to the appropriate authority
 - reviewing the person's plan of care to ensure that they are properly supported following the alleged abuse incident.
- Using information from safeguarding concerns to identify non-compliance, or any risk of non-compliance, with the regulations and to decide what will be done to return to compliance.
- Working collaboratively with other services, teams, individuals and agencies in relation to all safeguarding matters and has safeguarding policies that link with local authority policies.
- Participates in local safeguarding children boards where required and understand their responsibilities and the responsibilities of others in line with the Children Act 2004.
- Having clear procedures followed in practice, monitored and reviewed in place about the use of restraint and safeguarding.
- Taking into account relevant guidance set out in the Care Quality Commission's Schedule of Applicable Publications
- Ensuring that those working with children must wait for a full CRB disclosure before starting work.
- Training and supervising staff in safeguarding to ensure they can demonstrate the competences listed in Outcome 7E of the *Essential Standards of Quality and Safety*, 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 Sexually Transmitted Infections (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 except where safeguarding procedures do not allow this
- **A16.13** When a child is in hospital for more than five days, play is managed and supervised by a qualified Hospital Play Specialist.
- **A16.14** Children are required to receive education when in hospital for more than five days; the Local Education Authority has an obligation to meet this need and are contacted if necessary.
- **A18.10** There are written procedures for the assessment of pain in children and the provision of appropriate control.

All hospital settings should meet the *Standards for the Care of Critically Ill Children* (Paediatric Intensive Care Society, London 2010).

There should be age specific arrangements for meeting Regulation 14 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010. These require:

- A choice of suitable and nutritious food and hydration, in sufficient quantities to meet service users' needs;
- Food and hydration that meet any reasonable requirements arising from a service user's religious or cultural background.

- Support, where necessary, for the purposes of enabling service users to eat and drink sufficient amounts for their needs.
- For the purposes of this regulation, “food and hydration” includes, where applicable, parenteral nutrition and the administration of dietary supplements where prescribed.
- Providers must have access to facilities for infant feeding, including facilities to support breastfeeding (Outcome 5E, of the *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010)

All paediatric patients should have access to appropriately trained paediatric trained dieticians, physiotherapists, occupational therapists, speech and language therapy, psychology, social work and CAMHS services within nationally defined access standards.

All children and young people should have access to a professional who can undertake an assessment using the Common Assessment Framework and access support from social care, housing, education and other agencies as appropriate

All registered providers must ensure safe use and management of medicines, by means of the making of appropriate arrangements for the obtaining, recording, handling, using, safe keeping, dispensing, safe administration and disposal of medicines (Outcome 9 *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010). For children, these should include specific arrangements that:

- ensure the medicines given are appropriate and person-centred by taking account of their age, weight and any learning disability
- ensure that staff handling medicines have the competency and skills needed for children and young people’s medicines management
- ensure that wherever possible, age specific information is available for people about the medicines they are taking, including the risks, including information about the use of unlicensed medicine in paediatrics.

Many children with long term illnesses have a learning or physical disability.

Providers should ensure that:

- They are supported to have a health action plan
- Facilities meet the appropriate requirements of the Disability Discrimination Act 1995
- They meet the standards set out in *Transition: getting it right for young people. Improving the transition of young people with long-term conditions from children's to adult health services*. Department of Health Publications, 2006, London

Paediatric Care Guidelines**The Care of Children in Hospital (from HSC 1998/238)**

- Children are admitted to hospital only if the care they require cannot be as well provided at home, in a day clinic or on a day basis in hospital;
- Children requiring admission to hospital are provided with a high standard of medical, nursing and therapeutic care to facilitate speedy recovery and minimize complications and mortality;
- families with children have easy access to hospital facilities for children without needing to travel significantly further than to other similar amenities;
- children are discharged from hospital as soon as socially and clinically appropriate and full support provided for subsequent home or day care.
- Good child health care is shared with parents/carers and they are closely involved in the care of their children at all times unless, exceptionally, this is not in the best interest of the child; accommodation is provided for them to remain with their children overnight;
- Accommodation, facilities and staffing are appropriate to the needs of children and adolescents and separate from those provided for adults. Where possible separate accommodation is provided for adolescents; like all other patients, children have a right to their privacy to be respected and to be treated with tact and understanding. They have an equal right to information appropriate to their age, understanding and specific circumstances.
- There are at least two Registered Sick Children's Nurses (RSCNs) (or nurses who have completed the child branch of Project 2000) on duty 24 hours a day in all hospital children's departments and wards.
- There is a RSCN available 24 hours a day to advise on the nursing of children in other departments.

In Patient Care

- Wherever possible children undergoing surgical repair of clefts should be accommodated in a children's surgical environment to reduce the risk of transmitting infection from children admitted as medical emergencies;
- Resident paediatric staff, who are experienced in the management of fluid balance, post-operative pain control, and other postoperative problems, must be available at all times;
- The care of children who in very exceptional circumstances are not accommodated in a comprehensively staff children's unit, or who are dependent on nursing care, must be provided in accordance with the standards set out in the 'Welfare of Children and Young People in Hospital', by nurses who have up-to-date training in paediatric resuscitation;
- Anaesthetic services should be provided or supervised by an anaesthetist with paediatric expertise. The anaesthetist should have adequate opportunity to assess

the child before surgery and there should be appropriate facilities and equipment available for post-operative monitoring;

- Play therapists should be familiar with the investigations and the treatment which the child will experience and provide optimal preparation for them.

Facilities for parents and children

- Some children will live at a distance from the centre where they receive in-patient care. It is therefore important that there are adequate facilities for parents and siblings.
- Families should have an opportunity to visit the ward before admission and should be given information about the organisation and administrative arrangements for the hospital stay as well as the clinical procedures which are planned;
- Families should be provided with accommodation and support, with access to meals and refreshment services;
- Parents should be informed about the hospital travel costs scheme;
- A designated member of staff should inform parents about benefits and other assistance which may be available to them.

Out-patient medical and dental care

Ideally, children receiving out-patient hospital care or dental care should be seen in a separate children's clinic area which is suitably equipped. If this is not possible, and children have to be seen during an adult clinic session, their appointments should be "clustered" preferably at the beginning of the session. A discrete area in the adult department should be designated for the exclusive use of children. Toys and diversionary activities should be available. The clinic staff should include a cleft specialist nurse or a nurse experienced and skilled in the management of children.

Patient consent

The provider will ensure that patients with Cleft Lip and/or Palate and their family/carers are given as much information as they require, at the appropriate time, to support shared decision-making with their clinician about the range of treatment options available to them.

Where a patient has been assessed by the provider as unable to give consent to treatment the provider shall act in accordance with the consent requirements which include acting in the patient's best interest.

Patient choice

The provider will ensure that the Cleft Lip and Palate service is shaped around the preferences of patients, their family/carers and in compliance with eligibility criteria, clinical practice guidelines and within the scope of treatments offered.

Transition Care Service requirements

The provider will recognise that the transition of children/young people to adult services will need to be planned and managed well in advance of the actual transfer to ensure that the service remains responsive to the specific needs of this patient group.

Safeguarding Children, Young People and Adults

See Specification for Children's Services Appendix 5.

Social work support

The provider will refer patients / children / families for social work advice as required.

Local Care Guidelines

The service described in this specification relies on local CCG/local authority commissioned services to deliver some elements of the CLP pathway. It is possible that some of the services described in this appendix will be commissioned at a local level to support the nationally commissioned CLP services.

The service will work as a 'Hub and Spoke' model with all cleft surgery taking place at the specialist centres (Hub) and all core disciplines being centred at and directed from the Hub, notwithstanding that some centres are twin site.

Services may be delivered by Hub clinicians in the centre or by outreach, but to reduce travelling for patients who live distant from the centre, may be delivered by local specialist clinicians working as prescribed by hub clinicians, for example in SLT, dentistry, orthodontics, ENT/Audiology. Those services for cleft related care in those specialties/disciplines will be prescribed and coordinated by the Hub for local delivery of the clinical pathway in a timely and appropriate manner. These pathways will be based on national policy, guidelines and best practice. Such therapy should be delivered according to prescription by the hub cleft team for as long as considered necessary in the prescription and within timely fashion (no more than 18 weeks wait).

Orthodontics

Orthodontic treatment of patients with clefts should be considered in two broad categories:

1. Clefts not involving the alveolus: Orthodontic treatment for patients where the cleft does not involve the alveolus, or where it is anticipated that the orthodontic treatment will not require to be integrated significantly with surgery or other MDT care, may be provided at the Cleft Centre or locally by a suitably trained Consultant Orthodontist with the agreement of the Lead Cleft Orthodontist.
2. Clefts involving the alveolus: For patients with clefts involving the alveolus or where it is anticipated that treatment needs to be integrated with care provided by other members of the Multi-disciplinary Team, such as orthognathic surgery, speech and language therapy, it is more appropriate for treatment to be provided by one of the following:
 - Lead Cleft Consultant Orthodontist
 - A Post-CCST Specialty Trainee (in the final two years of training leading to consultant post) under the supervision of the Lead Cleft Consultant Orthodontist
 - A local Consultant Orthodontist participating in hub or outreach CLP clinics or a Post-CCST Specialty Trainee being supervised by them and in close co-operation with the Lead Cleft Consultant Orthodontist
 - Under a shared care arrangement with a local Consultant Orthodontist where significant amounts of the care are provided by the Lead Cleft Consultant Orthodontist with perhaps alternate appointments provided locally.

Orthodontic treatment of patients with CLP is not currently included in the first three years of orthodontic specialist registrar training. Consequently, treatment for these patients is provided either by a Consultant Orthodontist or under supervision by Post-CCST Specialty Trainees in Orthodontics. It is not appropriate for specialist practitioners, dentists with a special interest, or orthodontic therapists to treat patients with a cleft whose treatment is outside their training.

The provision of orthodontic treatment for patients with clefts, with or without alveolar involvement, must be agreed by the Cleft MDT and in those cases which will involve orthognathic surgery, that team must include the Cleft Surgeon/s who will carry out the orthognathic surgery, a team speech and language therapist and a team clinical psychologist.

Any local orthodontics will be provided in timely fashion and in no case will any patient wait longer than 18 weeks to start treatment. The treatment will conform to the overall cleft care pathway and will be guided by the Lead Cleft Consultant Orthodontist.

Speech and Language Therapy

The local speech and language therapy provided by specialist cleft link therapists or generalist community therapists will be appropriate to the needs of the individual child or adult and within 18 weeks RTT. Advice, support and guidance will be given to local therapists as required by the specialist speech and language therapists working at the cleft surgical centre.

ENT and Hearing

It is recognised that most ENT and Hearing investigation and treatment for cleft children will be carried out by local secondary services in ENT, Audiological Medicine and Audiology. Each locality should have designated individuals who have these responsibilities for cleft children and who will liaise closely with the central cleft team.

All children, regardless of whether they have a cleft palate, will undergo a New Born Hearing Screen locally within 1-3 days of birth.

All children with a cleft palate should also have their hearing assessed by a clinician trained in paediatric audiology between 8-10 months of age. They should receive follow-up audiological care and appropriate audiometric assessments not less frequently than once a year for the first 3 years, again at school entry and at 5 years and 10 years of age. In many centres the audiological and otological assessments for 5 and 10 year olds will be carried out at their respective Cleft MDT clinics (if not already performed locally). Local results will be shared with the cleft team for audit purposes.

All families of children with a cleft palate (including cleft lip and palate) should receive information about the risks of hearing loss and how to look out for it before the child is 10 months old.

All children with persistent conductive hearing loss must receive careful review by a clinician expert in otoscopy.

Dentistry

It is expected that the majority of dental care for cleft children and adults will be delivered locally through the general dental services and community dental services. It is important that children with CLP receive good and regular dental care and liaison with the cleft team and especially the specialist in paediatric dentistry will facilitate this.

APPENDIX 3



Health Service Circular Series: HSC 1998/238

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Status: Action

sets out a specific action on the part of the recipient with a deadline where appropriate

Cleft lip and Palate Services

Commissioning Specialised Services

For action by:

Health Authorities (England) - Chief Executives NHS Trusts - Chief Executives Regional Directors Primary Care Groups (via Health Authorities)

For information Health Authorities (England) – Chairs to:

NHS Trusts - Chairs Health Authorities - Directors of Public Health NHS Trusts - Medical Directors Local Medical Committees Local Dental Committees Community Health Councils - Chief Officers

Further details David Gilbert from:

NHS Executive Room 414 Wellington House 133-155 Waterloo Road London SE1 8UG 0171-972 4833

Additional copies of this document can be obtained from:

Department of Health PO Box 410 Wetherby LS23 7LN, Fax 0990 210 266

It is also available on the Department of Health website at

<http://www.doh.gov.uk/publications/coinh.html>

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Commissioning Specialised Services

Summary

1. HSC(1998)198 set out the arrangements for commissioning services in 1999-2000 and identified cleft lip and palate services as a national priority for the new arrangements for commissioning specialised services.
2. This HSC provides a Commissioning Framework (attached as Annex A) to ensure that the recommendations of the Clinical Standards Advisory Group (CSAG) on cleft lip and palate services are implemented and outlines the process which will ensure that these services are in place no later than 1 April 2000.

Action

3. Regional Offices will evaluate the current provision of cleft lip and palate services, have a key role in determining the precise nature of the revised commissioning arrangements and will monitor implementation in line with the Commissioning Framework.
4. Health Authorities should cooperate with Regional Office Cleft Leads (see Annex 3), to identify as soon as possible the main centres for the provision of services, which meet the criteria set out in the Commissioning Framework. HAs should also bring this HSC to the attention of Primary Care Groups (PCGs).
5. NHS Trusts currently providing cleft lip and palate services should note that the designation of the main centres will take place as soon as possible. Once main centres have been identified, all NHS Trusts should review their services and facilities and ensure that they only provide services which are consistent with the Commissioning Framework. Trusts designated, as main hub centres should put in place an appropriate network of care involving spoke units.

Points to Note

6. The revised commissioning arrangements must take full account of CSAG's recommendation to reduce significantly the number of units currently carrying out cleft surgery and ensure there is a smooth transition for patients and for the units that will no longer provide this service. Main centres should be based where the needs of patients can be best met, taking into account the availability of appropriate expertise in all the relevant specialities, as well as patient access.
7. There should be a clear understanding about the balance of care between main centres and local services. Commissioners should ensure that NHS Trusts develop networks between the main centre, local providers (spokes) and primary care practitioners.
8. Once the revised commissioning arrangements are in place, new patients should be treated in line with the Framework's specification. Patients already receiving care may choose to continue to be treated under existing arrangements, as long as that remains a viable option.

9. The Cleft Implementation Group (listed at Appendix 3 of the Framework), set up by HSC 1998/087, will continue to meet to oversee the transitional period. The role of the Group is to ensure that reconfiguration proposals are in line with the CSAG report and the Commissioning Framework. The Group will be available to provide direction and advice as required.

Background

10. CSAG's report on Cleft Lip and/or Palate was published on 23 February 1998 together with the Government's response (HSC 1998/002). A major Recommendation from CSAG, accepted by the Government, was that expertise and resources for cleft lip and palate services should be concentrated at between 8 and 15 centres throughout the United Kingdom. An Implementation Group was established by the NHS Executive and Welsh Office (HSC 1998/087) to support and facilitate the necessary changes in England and Wales. The Commissioning Framework has been developed by the Implementation Group to provide the basis of a specification which should be used to commission cleft lip and palate services.

Questions and Correspondence

11. Any questions or correspondence about this Circular or the Commissioning Framework should be sent to:

David Gilbert
NHS Executive
Room 414 Wellington House
133-155 Waterloo Road
London SE1 8UG

Telephone: 0171-972 4833

Associated Documentation

HSC 1998/198 set out the arrangements for commissioning services in 1999- 2000.

HSC 1998/087 announced the establishment of an implementation group to develop a commissioning framework for services for children born with a cleft lip and/or palate.

HSC 1998/002 covered the Clinical Standards Advisory Group (CSAG) report on Cleft Lip and/or Palate together with the Government's response.

This circular has been issued by:

Dr Graham Winyard
Director of Health Services

A Commissioning Framework for Cleft Lip and Palate Services**Introduction**

This Framework has been drawn-up by the Cleft Implementation Group (see Appendix 3) which was established to support and facilitate the changes recommended by the Clinical Standards Advisory Group (CSAG) in its report on Cleft Lip and/or Palate.

Regional Offices should use this Framework in evaluating the current provision of cleft lip and palate services in their Region and in designating main cleft centres. The Framework is based on the new NHS performance guidelines and the 14 criteria identified in the CSAG report which were used as a basis for assessing the 17 centres visited by the CSAG steering committee.

1. Health Improvement & Outcomes

Cleft centres should be able to demonstrate positive health outcomes. Quality and audit should be at the heart of the services being provided. In order to demonstrate health outcomes it is essential that an appropriate information and audit database is maintained at each main centre. Lead commissioners may then use the information obtained to monitor the contract and modify the service specification as appropriate.

1.1 Information

All patients' records must be maintained at the main centre including study models, relevant radiographs, clinical photographs, speech recordings and videotaped investigations of velopharyngeal function etc.

The CSAG report identified the need for more complete recording of cleft births in the UK by ONS. Commissioners should ensure that adequate arrangements for notification exist in all maternity units and that community midwives and primary care teams are aware of the arrangements for notification.

1.2 Clinical Audit

A Craniofacial Anomalies Register (CARE), with which all patients should be registered, will be maintained by the Craniofacial Society of Great Britain and this will form the basis for national audit.

Cleft centres should ensure that they have rigorous systems in place for clinical audit. The involvement of centres in national, inter-centre, audit is essential and their involvement in international audit is to be encouraged. Records should therefore be maintained in a form that supports both national and international audit.

The registration and audit processes should establish the proportion of patients who are lost to follow up.

Audit outcomes must be available for commissioners and the results should be independently assessed on a regular basis by agreed and standard assessment techniques.

2. Fair Access

The development of services based on a small number of main centres as the focal point for a network of services will inevitably affect access for some patients and their carers. However the key principle must be that aspects of care which require special facilities and expertise which cannot reasonably be provided as outreach or spoke services, such as the primary and secondary surgery, should only be provided in the main centres. Other aspects of care which depend on regular contact, such as speech and language therapy and orthodontic care, may be provided locally. This can be through 'outreach' by clinicians from the main 'hub' centre travelling to local clinics or by suitably trained clinicians from the 'spokes' working as part of the service network, but clearly linked with the main 'hub' team.

Formal and regular communications are needed between the main 'hub' team and clinicians in the 'spokes' as part of the communications strategy. Consideration should be given to the use of telemedicine where appropriate.

In approving the main centres, Regional Offices should consider how the proposed service network will ensure the best balance between services at the main centre and those provided locally, through joint agreement between providers and commissioners.

Main centres are expected to ensure that arrangements for parents, including the provision of accommodation, take account of access and are in accordance with those expected of tertiary paediatric centres. Advice should be available on the benefits, which may be available to families including the hospital travel costs scheme.

3. Effective delivery of appropriate health care

3.1 Key responsibilities and skill mix of a Main Team

The care of all cleft lip and/or palate patients should be organised by multidisciplinary teams which should see at least 80 to 100 new cases each year.

The main team should be led by a clinical director and should include:

- A care co-ordinator/manager of the regional cleft service
- Two lead surgeons who will each undertake primary surgery on an average of 40-50 new patients each year
- A surgeon specialising in secondary surgery such as bone grafting and orthognathic surgery

- A lead orthodontist having a major commitment to cleft care
- A lead Speech and Language Therapist with a major commitment to cleft care
- A lead paediatrician having a major involvement with the cleft team ensuring good paediatric surveillance and ongoing paediatric care
- An ENT surgeon with paediatric experience
- An audiological physician
- A specialist registered paediatric nurse or health visitor with responsibility for providing feeding advice and support to parents, and the co-ordination of nursing activities
- An appropriately trained psychologist

Ideally a main team should be based at a cleft 'hub' centre on one site. In some areas it might, for reasons of geography and access, be necessary to have a main centre providing care on two sites. It would not be satisfactory for a cleft centre to be spread over more than two sites. A cleft centre must provide adequate administrative, secretarial and audit support for the cleft team.

The extended team should include a geneticist, an ultrasound diagnostician, a paediatric dentist, a restorative dentist, and maxillofacial and orthodontic technologists.

The main team must agree 'hub', 'outreach' and 'spoke' arrangements with commissioners and local providers. Care in the hub centre will be provided by the main team and by other practitioners linked to the extended team. The main team may provide 'outreach' services on other sites. The main team should also specify the range of services to be provided by other practitioners on distant sites (the spoke teams).

The main team is responsible for ensuring close liaison with the extended team and monitoring the quality of care undertaken by the extended team including the appropriate training and accreditation of staff. Members of the main team should be able to provide on-call support to local providers in their spoke network, which may include outreach visits. There should be effective communications between the cleft team and other professionals with specialist knowledge of the care of babies and children.

Surgical cleft lip and palate care should be provided in paediatric centres with appropriate paediatric nursing and paediatric anaesthetic support as defined in 3.3.10. Hub centres must always have either a full range of paediatric intensive care facilities or a protocol for transfer of the few patients who need paediatric intensive care.

There should be a *service directory* readily available for patients, parents, all staff within the hospital and other professionals (e.g. GPs, GDPs, Community Paediatricians, Community Midwives, Health Visitors etc.) which identifies members of the cleft team including the extended team. The directory should cover both the services available at the main centre and across the extended network.

3.2 Care Pathways

Centres will need to demonstrate that they have written guidelines for care from the prenatal period to maturity and that there is continuity of care from members of the same team. The guidelines should clearly identify those aspects of care that must be provided in the main centres and those that may be provided locally through the 'outreach' or 'spoke' arrangements. Appendix 1 shows the appropriate locality for care at various stages through the care pathway.

3.3 Specific Services to be provided in the Hub Centres

3.3.1 Psychological & Counselling Services

- **Pre-natal Support** Members of the main team have an important role to play in counselling and supporting parents at the time of diagnosis. Centres must be able to demonstrate that appropriate pre-natal support services are provided to all local obstetric units/ultrasound units including access to main team members (see also 3.4.1)
- **Continuing Care** The psychologist should play a central role in achieving good outcomes in cleft care through routine psychosocial assessment and through the prevention and treatment of psychological problems. Psychosocial, patient centred audit and outcome measures should be included in each centre's record keeping system.

3.3.2 Genetic Services

The aim of a clinical genetics service is to provide information, diagnosis, counselling, management and support to patients and families with genetic disorders.

A named geneticist should be attached to every main cleft team and be readily available to give advice in respect of the diagnosis and genetic testing (cytogenetic and molecular) for all patients referred to the cleft team.

Both the patient and the parents should be offered, at the appropriate time, genetic counselling regarding the diagnosis and risk to offspring and the possibilities for prenatal diagnosis. Such counselling needs to be built into the continuum of the child's care in a structured formal manner.

3.3.3 Primary Surgical Repair

The standard of primary surgery is crucial to the quality of outcome. Potential cleft centres must be able to demonstrate that surgeons undertaking primary surgery have appropriate experience and training, a proven commitment to cleft care, the ability to work within a team and be able to have demonstrate and maintain good outcomes. Each surgeon will undertake surgery on an average of 40-50 new patients each year.

All primary surgery should be undertaken within a paediatric environment with care being provided by paediatric trained specialist staff (see also 3.3.10 and Appendix 2).

Units must undertake an audit of outcomes of surgery and ensure that these are available for review by the commissioners (see also 1.2).

3.3.4 Speech and Language Therapy

Centres should ensure that care is led by an experienced specialist Speech and Language Therapist who is a member of the main cleft team. Specialist speech and language assessment, diagnosis and decision-making regarding intervention (usually surgical and/or therapy intervention) should be available. Active therapy should be undertaken by the hub speech and language therapy team who must maintain their therapy skills particularly where there are complex issues of management. Appropriate specialist equipment should be available, regularly and correctly used, with appropriate archiving of records. There should be regular joint surgeon/speech and language therapist/prosthodontist speech investigation clinics.

The hub speech and language therapy team should maintain complete speech records and the lead therapist on the main team should be responsible for audit and research activities related to speech outcomes (also see 3.3.9)

3.3.5 ENT and Audiology Services

Assessment and management of hearing problems should be provided at all ages and co-ordinated by the main centre with advice from the ENT surgeon on the team. Routine assessment should be provided as part of the programme of regular clinic visits. Results of audiology assessment should be included in the record system.

3.3.6 Orthodontic Services

An orthodontic assessment is required for all children and should be undertaken at the main centre where joint consultation can take place with other members of the team. Centres must therefore demonstrate that they can provide orthodontic care at appropriate stages by an experienced orthodontist specialising in cleft care.

Appropriate orthodontic records at all stages of care must be collected and archived in the main centre. Patients should attend the main centre for the collection of all records, including orthodontic study models at five, ten, fifteen and twenty years. If necessary for completeness, records may need to be duplicated in the spoke units and archived centrally (also see 3.3.9)

3.3.7 Dental Services

Maintaining good oral health is essential for children with clefts. Units must demonstrate that preventive advice is provided including the use of fluoride supplementation where appropriate. A paediatric dental specialist and a consultant in restorative dentistry should provide advice and treatment as required by the cleft team (see also 3.4.6).

3.3.8 Secondary Surgery

There are two main areas of secondary surgery:

- Alveolar bone grafting and orthognathic surgery
- Velopharyngeal surgery and soft tissue surgery including revisional rhinoplasties.

These should be undertaken by a surgeon who is a member of the main team at the centre. The surgeon must have appropriate experience and training with a proven commitment to cleft care, the ability to work within a team and be able to demonstrate and maintain good outcomes.

3.3.9 Records

The maintenance of good records is essential if the quality of cleft care is to be assured. A high priority should be accorded to obtaining excellent records which should remain at and be the responsibility of the main centre. Co-ordinated record keeping is necessary to enable inter-centre audit to be undertaken (see Section 1.1). 'Information for Health' sets out the Government's strategy for improving patient information systems and for the development of on-line electronic patient records. In the meantime consideration could be given to the provision of patient held records. For younger children this could include a summary record inserted in the booklet "A Personal Child Health Record".

3.3.10 Paediatric Environment

All children receiving cleft care should be treated in an appropriate paediatric environment, the general features of which are set out in Appendix 2, which also includes a list of sources of more detailed advice. In addition, there are some specific features which are necessary for high quality cleft care.

Community Based Care

Most general practitioners, general dental practitioners, and primary care teams have limited experience of the care of children with cleft lip and/or palate. They are however, important sources of advice and support to parents and will be responsible for the coordination of general health care services for the child. It is therefore important that, at the time of diagnosis or birth, the child's general practitioner should be sent information about the cleft team and the general principles of care offered by the cleft team. The general practitioner and other colleagues in the primary care team should be kept informed about the child's treatment and progress.

An early feeding assessment and an appropriate plan of care should be made by the specialist cleft nurse normally within 24 hours of the birth of a child with a cleft. This must be in conjunction with the midwives, neonatal nurses and paediatrician with responsibility for the baby as well as with the primary care team. The primary care team should have access to the multi-disciplinary cleft team and should be given appropriate information on

discharge from hospital as well as throughout the child's care. Initial feeding equipment should be provided for parents. Families must be given ongoing advice and support integrated with a counselling service, if needed, from the extended team or health visitor and their team. Paediatric community nursing services should be available for children with associated anomalies.

In Patient Care

Wherever possible children undergoing surgical repair of clefts should be accommodated in a children's surgical environment to reduce the risk of transmitting infection from children admitted as medical emergencies;

Resident paediatric staff, who are experienced in the management of fluid balance, post-operative pain control, and other postoperative problems, must be available at all times;

The care of children who in very exceptional circumstances are not accommodated in a comprehensively staff children's unit, or who are dependent on nursing care, must be provided in accordance with the standards set out in the 'Welfare of Children and Young People in Hospital', by nurses who have up-to-date training in paediatric resuscitation;

Anaesthetic services should be provided or supervised by an anaesthetist with paediatric expertise. The anaesthetist should have adequate opportunity to assess the child before surgery and there should be appropriate facilities and equipment available for post-operative monitoring;

Play therapists should be familiar with the investigations and the treatment which the child will experience and provide optimal preparation for them.

Facilities for parents and children

Some children will live at a distance from the centre where they receive in-patient care. It is therefore important that there are adequate facilities for parents and siblings.

- Families should have an opportunity to visit the ward before admission and should be given information about the organisation and administrative arrangements for the hospital stay as well as the clinical procedures which are planned;
- Families should be provided with accommodation and support, with access to meals and refreshment services;
- Parents should be informed about the hospital travel costs scheme;
- A designated member of staff should inform parents about benefits and other assistance which may be available to them.

Out-patient medical and dental care

Ideally, children receiving out-patient hospital care or dental care should be seen in a separate children's clinic area which is suitably equipped. If this is not possible, and children have to be seen during an adult clinic session, their appointments should be "clustered" preferably at the beginning of the session. A discrete area in the adult

department should be designated for the exclusive use of children. Toys and diversionary activities should be available. The clinic staff should include a cleft specialist nurse or a nurse experienced and skilled in the management of children.

Diagnostic procedures

Patients and children should be given information about the diagnostic procedures which may be necessary as part of the clinical management and prepared accordingly.

The Care of Young People

The management of cleft lip and/or palate may require surgical or dental interventions into adult life. Young people may still need to be seen by the cleft team and there should be flexibility in the organisation which takes account of their needs and views, and offers a choice between an adult or children's setting for the most appropriate delivery of services.

3.4 Services provided as 'outreach' and by the 'spokes'

Some services can be provided by the main team doing outreach work outside the setting of the cleft centre to ease the burden of travelling on parents and patients. Other aspects of care can be provided in the 'spokes' by less specialised practitioners. When care is offered by the spokes it is essential that there is close liaison with the cleft team at the main centre who should take responsibility for assessing and auditing the quality of the care provided. Services provided outside the cleft centre may be in hospitals or in primary care settings.

3.4.1 Pre-natal diagnosis & management

Approximately 20-25% of cleft lips and palates are now diagnosed prenatally by ultrasound scanning. Centres must therefore be able to demonstrate that appropriate outreach pre-natal diagnostic support services are provided to local obstetric/ultra- sound units. Professionals undertaking scanning should have a knowledge of cleft lip and palate. Confirmation and classification of the diagnosis should be made by an ultrasound diagnostician who is either a member of the cleft team or who is recognised as having a special interest in prenatal cleft diagnosis. The diagnosis and level of confidence in the classification of the clefting should be communicated to the main cleft team and thence to the parents as rapidly as possible. There should be a written protocol in place for informing parents of the diagnosis. Arrangements should be made for parents to be put in contact with a member of the cleft team within 24 hours.

3.4.2 Counselling Services

Counselling should only be undertaken by appropriately trained professionals experienced in cleft lip and palate care. Good communication with the psychologist on the main team at the hub is essential.

Carer groups are very concerned about conflicting advice provided by health professionals not connected with the cleft team. Specialist advice and counselling for parents should be provided from the time of diagnosis by a designated member of

the cleft team who should ensure that an around-the-clock system is in place for maternity units, community midwives and primary care teams to contact the designated member(s) of the cleft team. Each maternity unit should designate a link nurse to liaise with the cleft team, ensure all staff in the maternity unit are familiar with the contact arrangements and maintain an up to date knowledge and understanding of cleft conditions.

Patient information leaflets should be available in maternity units, ultrasound departments and foetal medicine units.

3.4.3 Audiology

Hearing assessments must be undertaken as part of the routine neonatal child assessments. These can be undertaken in spoke hospitals or other neonatal/obstetric units if suitable facilities are available.

3.4.4 Speech and Language Therapy

Early monitoring and advice will be provided wherever possible in spoke clinics or the community under the guidance of, and in collaboration with, one of the hub-team speech and language therapists. Therapy programmes will often be carried out at the spoke but a proportion of complex cases will need to be seen in the main centre. Specialist therapy in partnership with the local therapist should be available as an integral part of the network of services.

3.4.5 Orthodontics

Orthodontic care may be provided at sites other than the centre, according to jointly agreed protocols. The orthodontist at the cleft centre should take the lead in determining appropriate treatment plans consistent with the protocol of care and will be responsible for the maintenance of appropriate central records and for clinical audit.

3.4.6 Continuing Dental Care

Preventive dental advice and fluoride supplementation should be provided to cleft patients throughout childhood. Normally advice and any necessary treatment will be provided by specialists in paediatric dentistry. Primary care dentists should have ready access for referral to consultants in paediatric and restorative dentistry when required.

4. Efficiency

In common with other services, cleft centres should be able to demonstrate that the cleft lip and palate service is delivered as efficiently as possible and is providing value for

money. Centres should introduce benchmarking as a means of comparing performance and for sharing best practice. It is essential that resources should be sufficient to achieve good standards of care and there should be effective, efficient and open management.

5. Patient/Carer Experience

The CSAG report included information from surveys of parents who reported that confusion and distress is caused to some families because incorrect information is given to them by health professionals who are not experienced in cleft care. The report also identified the important role that support groups play under the umbrella of the Cleft Lip And Palate Association (CLAPA). Cleft centres will need to demonstrate:

- working relationships with national and local voluntary groups including provision of support and information
- up to date information and education resources for parents appropriate to their needs

6. Education and Training

Services should be consultant led and staffed. A main cleft centre would be expected to provide specialist staff training for surgical, orthodontic, speech and language therapy, psychologists and nursing staff.

Lead clinicians should be able to demonstrate a commitment to continuing professional education and training for all staff involved in the network of provision of cleft care.

Where surgical and orthodontic trainees participate in care this should be as part of a defined training programme and only in centres recognised by the appropriate Royal Colleges and Faculties for higher training in cleft lip and palate care. Inter-speciality assessment will be important to ensure joint recognition of centres.

APPENDIX 1

Cleft lip and Palate Services: Care Pathways & Location of Care

	Ante-natal	Birth to 3 months	4 to 18 months	18 months to 5 years	6 to 10 years	11 to 20 year	21 years
LOCAL OBSTETRIC UNITS	<ul style="list-style-type: none"> • Diagnosis with ultrasound imaging confirmed by Specialists from main centre • Contact with Cleft Team within 8 hours 	<ul style="list-style-type: none"> • Contact with Cleft Team 					
MAIN "HUB" CLEFT CENTRES	<ul style="list-style-type: none"> • Contact by Cleft Team within 24 hours 	<ul style="list-style-type: none"> • Visit within 24 hours of birth • Specialist feeding advice • Cleft team meets parents • Lip repair 	<ul style="list-style-type: none"> • Closure of palate • ENT assessment and management if necessary 	<ul style="list-style-type: none"> • Speech and language assessment and management, • ENT assessment and audiology management if necessary • Psychological support prior to school entry • Surgery to revise lip and velopharyngeal surgery if necessary • Full set of records at 5 	<ul style="list-style-type: none"> • Orthodontic assessment • Alveolar bone grafting together with associated orthodontic care • Surgery to revise lip and velopharyngeal surgery if necessary • Psychological support prior to school transfer • Speech and 	<ul style="list-style-type: none"> • Definitive orthodontic care • Team assessment for orthognathic surgery • Planning and pre-treatment for skeletal surgery • Appropriate surgery as required e.g. soft tissue, nasal, implants 	Record of any skeletal surgery

	Ante-natal	Birth to 3 months	4 to 18 months	18 months to 5 years	6 to 10 years	11 to 20 year	21 years
				years	<ul style="list-style-type: none"> hearing problems managed Review by main team Records at 10 years to include orthodontic treatment 	<ul style="list-style-type: none"> Ensure complete set of records at 15 and 20 year 	
"SPOKE" UNITS		<ul style="list-style-type: none"> Neo-natal hearing test Genetic counselling to parents 	<ul style="list-style-type: none"> Speech and language therapy assessment 	<ul style="list-style-type: none"> Speech & Language Therapy ENT and audiology assessment if necessary 	<ul style="list-style-type: none"> Speech and hearing problems managed 	<ul style="list-style-type: none"> Continuing orthodontic treatment paediatric and restorative dental care close liaison with "centre" 	
PRIMARY CARE		<ul style="list-style-type: none"> Dental health education in liaison with main centre 	<ul style="list-style-type: none"> Dental health education in liaison with main centre 				
			<ul style="list-style-type: none"> Routine child health surveillance Routine hearing test at 8 months 	<ul style="list-style-type: none"> Routine preventive dental advice and treatment Speech & Language Therapy 	<ul style="list-style-type: none"> Routine preventive dental advice and treatment Speech & Language Therapy 	<ul style="list-style-type: none"> Regular dental care 	<ul style="list-style-type: none"> Regular dental care

APPENDIX 2

The Care of Children in Hospital

The Cleft Lip and Palate Implementation Group considers that all children should be cared for in a suitable paediatric environment and endorses current Government policy, as set out in "Welfare of Children and Young People in Hospital". The basic principles underpinning this policy are:

- 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 a speedy recovery and minimise complications and mortality;
- Families with children have easy access to hospital facilities for children without needing to travel significantly further than to other similar amenities;
- Children are discharged from hospital as soon as socially and clinically appropriate and full support provided for subsequent home or day care;
- Good child health care is shared with parents/carers and they are closely involved in the care of their children at all time unless, exceptionally, this is not in the best interests of the child;
- Accommodation is provided overnight for them to remain with their children
- Accommodation, facilities and staffing are appropriate to the needs of children and adolescents and separate from those provided for adults. Where possible separate accommodation is provided for adolescents;
- Like all other patients, children have a right for their privacy to be respected and to be treated with tact and understanding. They have an equal right to information appropriate to their age, understanding and specific circumstances.
- There are at least two Registered Sick Children's Nurses (RSCNs) (or nurses who have completed the child branch of Project 2000) on duty 24 hours a day in all hospital children's departments and wards.
- There is a RSCN available 24 hours a day to advise on the nursing of children in other departments.

This policy has been supported by the Audit Commission in its report "Children First" and by the Parliamentary Select Committee. The following bibliography sets out sources of further information about the care of children and young people.

References

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- House of Commons (1997) Health Committee, Fifth Report, Hospital Services for Children and Young People, The Stationery Office Ltd, London.
- NHS The Patients' Charter, (1996) Services for Children and Young People, Department of Health

APPENDIX 3

Membership of the Cleft Implementation Group

Chairman

Dr June Crown Director South East Institute of Public Health Past-President , Faculty of Public Health Medicine

Members

- Ms Jackie Axelby Chief Executive Northumberland Health Authority
- Ruth Carnall Chief Executive West Kent Health Authority
- Mr Gareth Davies Chief Executive Cleft Lip and Palate Association
- Mr Barry Jackson President, Royal College of Surgeons (from September 1998)
Professor Malcolm Jones Head of Dental Health and Development, University of Wales
- Mr Paul Langmaid Chief Dental Officer Welsh Office
- Ms Vanessa Martin Senior Nursing Officer Nottingham City Hospital NHS Trust
- Dr Nichola Rumsey Research Director Centre for Appearance & Disfigurement Research, Bristol
- Dr Jonathan Sandy Reader in Orthodontics University of Bristol Dental Hospital & School
- Dr Debbie Sell Head of Speech & Language Therapy, Great Ormond Street Hospital for Children NHS Trust
- Dr Gunvor Semb Senior Lecturer in Craniofacial Anomalies, Manchester University
- Mr Brian Sommerlad President, British Association of Plastic Surgeons, Consultant Plastic Surgeon, St Andrews Hospital, Billericay, and Great Ormond Street Hospital for Children NHS Trust
- Sir Rodney Sweetnam President, Royal College of Surgeons (until August 1998)
- Mr Michael Wake Consultant Oral and Maxillofacial Surgeon, Birmingham Children's Hosp
- Secretariat
- Dr Val Chishty NHS Executive, London
- Mr Tony Jenner NHS Executive, North West Regional Office
- Ms Simone Bayes NHS Executive, London
- Mr David Gilbert NHS Executive, London
- Mr Roger Motton NHS Executive, London

ANNEX B

Regional Cleft Leads (From 1 January 1999)

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- Dr Mark Shackell Consultant in Dental Public Health/Regional Dental Adviser NHS Executive London 40 Eastbourne Terrace London W2 3QR Tel: 0171 725 2644 Fax: 0171 725 2666
- John Langford Assistant Director of Public Health/Regional Dental Officer NHS Executive West Midlands Bartholomew House 142 Hagley Road Edgbaston Birmingham B16 9PA Tel: 0121-224 4678 Fax: 0121-224 4680

APPENDIX 4

Speech Therapy Standards for Cleft Lip and/or Palate

Standards compiled and amended by Liz Albery, Melanie Bowden, Lorraine Britton, Anne Harding-Bell, Ginette Phippen and Debbie Sell, discussed at the Lead Speech and Language Therapists Forum October 2006 / May 2007, shared with primary surgeons for feedback Sept 2007, ratified by Lead SLT forum October 2007, piloted in 2008 and amended in 2009

Process Standards

1. 100% of children with cleft palate (+/- cleft lip/alveolus) who are eligible are offered assessment by a specialist speech and language therapist by 27 months old and this offer documented.
2. Speech records are taken in line with national audit recommendations and reported locally & nationally for all non-syndromic children with UCLP, BCLP, isolated cleft palate (including PRS) who are able to complete audit. Any exclusions are reported with reasons
3. For each audit cohort at age 5, 10, 15/18 yrs
 - All audit recordings are analysed by consensus by at least two CAPS A trained SLTs
 - A minimum of 10 consecutive recordings per centre involve a listener external to the centre either as part of the consensus group or independently.
 - All results are submitted to the CRANE database

Outcomes Standards

1. By 5 - 5.11 years 50% of children have speech within the normal range i.e. green profile on CAPS A.
2. By 5 - 5.11 years,
 - 70% of children have speech with no evidence of a structurally related problem (as defined below) and have not had VP surgery or fistula repair for speech

- 10% of children have had VP surgery or fistula repair and speech now has no evidence of a structurally related problem
 - 10% of children have had VP surgery or fistula repair & still have speech indicative of a structurally related problem
 - 10% of children have had no VP surgery or fistula repair and have current evidence of a structurally related problem
 - *NB Please identify number of cases with NT / NE only*
3. By 5 - 5.11 years more than 50% of children have no cleft type articulation difficulties which require therapy or surgery.
 4. By 10-10.11 years 80% of children have speech with no evidence of a structurally related problem irrespective of any surgical interventions
 5. By 10-10.11 years 80% of children have no cleft type articulation difficulties on CAPS A except 1 or 2 consonants affected by palatalisation and / or lateralisation

**Change Notice for Published Specifications and Products
developed by Clinical Reference Groups (CRG)**

Amendment to the Published Products

Product Name	Cleft Lip and/ or Palate Services including Non- Cleft Velopharyngeal Dysfunction (VPD) (All Ages)
Ref No	D07/S/a
CRG Lead	Adrian Sugar

Description of changes required

Describe what was stated in original document	Describe new text in the document	Section/Paragraph to which changes apply	Describe why document change required	Changes made by	Date change made
	As a result of moving to the new 2014/15 template an additional Section 2 and Appendix 1 has been added, linking service outcomes and standards of care to the NHS Outcomes Framework Domains.	Section 2 and appendix 1	New format specification	CRG	October 2013
	Domain 2 the following measure has been added ' % of parents who receive a visit from Clinical Nurse Specialist within 24 hours'	Page 4	Further clarification	CRG	October 2013

	Core Standard 1 for Antenatal care has been amended from 'Parents will be contacted by an appropriately skilled member of the cleft team' to 'Parents will be offered a visit from a CNS..'	Core Standard 1	Further clarification	CRG	October 2013
	Core standard 6 for Post natal and Infant has been changed from 'A Clinical Nurse Specialist or an appropriately skilled member of the cleft team should visit the mother and baby' to 'A Clinical Nurse Specialist should visit the mother and baby'.	Core Standard 6	Further clarification	CRG	October 2013