PAEDIATRICS

A NATIONAL MODEL OF CARE FOR PAEDIATRIC HEALTHCARE SERVICES IN IRELAND

CHAPTER 19: PAEDIATRIC CRANIOFACIAL SURGERY

Feidhmeannacht na Seirbhíse Sláinte
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ROYAL COLLEGE OF PHYSICIANS OF IRELAND

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19.0 INTRODUCTION

Parameters of care for craniosynostosis are well established internationally, and are outlined by McCarthy et al. (2012) in the Cleft Palate-Craniofacial Journal. Following an internationally agreed multidisciplinary consensus, the basic tenant for patients with craniofacial conditions is that their optimal care is best managed by interdisciplinary teams comprising of professionals from multiple disciplines:

1. Craniofacial surgery
2. Neurosurgery
3. Anaesthetics
4. ENT/airway
5. Genetics
6. Hand surgery
7. Plastic surgery
8. Nursing
9. Ophthalmology
10. Paediatric dentistry
11. Orthodontics
12. Prosthodontics
13. Maxillofacial
14. Speech & language therapy
15. Physiotherapy
16. Paediatrics
17. Radiology
18. Clinical photography

and supported by a clinical coordinator.

In 2008, Mr. Dylan Murray, Consultant Craniofacial, Plastic and Reconstructive Surgeon, was appointed as the lead clinician for the National Paediatric Craniofacial Centre (NPCC) at Temple Street Children's University Hospital (Temple Street), having completed his paediatric craniofacial fellowship at the world renowned Hospital for Sick Children in Toronto. Following this, Mr. John Caird was appointed as a Consultant Paediatric Neurosurgeon with a special interest in craniofacial surgery and childhood brain tumours. The NPCC has both formal and informal ties with other craniofacial centres internationally. As a small sub-specialty which deals with complex cases, it is imperative that these ties are maintained to enable research and provide a forum for discussions on development of the specialty, as well as ensuring that the staff at the NPCC maintain both the most up to date and highest standards in the care of children with craniofacial conditions.

The craniofacial team aim to provide a holistic multidisciplinary approach to the management of both congenital and acquired craniofacial deformity from birth to skeletal maturity using the most modern and advanced techniques. The service accepts referrals for assessment of all children suspected of having one of the following diagnoses, and the treatment and associated follow up of all those in whom the condition is confirmed:

- Craniosynostosis: syndromic and non-syndromic
- Positional plagiocephaly
- Encephaloceles
- Craniofacial tumours
- Facial asymmetry
- Growth disorders, e.g. congential micrognathia
- Facial clefts
- Craniofacial trauma
- Congenital and acquired facial palsy

Given the incidence of these rare conditions, they fall within the remit of the National Rare Disease Plan for Ireland (2014-2015).

The craniofacial team embraces family-centred care and values the family as equal partners in the decision making process and assuring quality care for the child. Early assessment of a child with craniosynostosis is vital. The NPCC aims to provide coordinated care from assessment through to treatment and/or intervention, with follow-up protocols in place at various timelines during the child's growth and development. Each patient journey is individualised encompassing medical, surgical, and psychosocial needs. The NPCC have developed an algorithm for the various craniofacial conditions with an outline of optimum surgical procedures (see Appendix 1) within specific time frames. This allows for craniofacial surgery as an integral component of the overall management of the child. The introduction of five day inpatient admission for multidisciplinary assessment of complex craniofacial patients has greatly improved the care pathway for these patients. This facilitates future care planning and has been shown to reduce the burden of care on families while establishing partnerships with primary care teams and regional hospitals.

19.1 CURRENT SERVICE PROVISION

In 2008, the unit performed over 20 complex cranial vault procedures and, at that time, a shared care model of treatment for children with syndromic craniosynostosis was in place so that a number of children with complex craniosynostosis could be cared for at the craniofacial unit in London every year. Since 2009, the range of surgical procedures carried out has extensively expanded (see Appendix 1), and Irish children requiring craniofacial surgery are cared for at the NPCC. In 2013, the NPCC performed over 65 complex craniofacial procedures and has been innovative in the development of cranial vault distraction procedures.

The NPCC is a national service, with referrals received from neonatologists, paediatricians, neurosurgeons, area medical officers, general practitioners (GPs), in-house paediatric subspecialists, the Royal Belfast Children's Hospital, and, where appropriate, overseas. The referral pathway includes triage by the consultant craniofacial surgeon and/or members of the multidisciplinary team. New referral consultation appointments are prioritised based on clinical presentation. Appointments are scheduled for craniofacial clinic consultations in a timely fashion based on a defined departmental structured protocol, i.e. 'urgent' appointments are scheduled for the next available clinic, 'soon' appointments are wait listed for consultation within three months, and 'routine' appointments are generally seen within a six month period.

Recently, the NPCC has expanded its services to include a significant unmet need in the country for the management of children with facial palsy, both congenital and acquired. This involves multidisciplinary team (MDT) clinics with follow-on surgery where indicated. This service will be run in conjunction with Consultant Cleft Surgeon Mr. Christoph Theopold, who also has a special interest in facial palsy and reanimation.

The craniofacial service provides weekly multidisciplinary team clinics, integrated care pathways and protocol-based scheduling of surgery adhering to international evidence-based best practice. The service also has close working links with multidisciplinary teams and clinics within Our Lady's Children's Hospital Crumlin (Crumlin) and St. James's Hospital, Dublin. Children are seen from neonatal stage to adolescence and, depending on their individual condition, will either be discharged following a final review in their 15th year, or transitioned to care services under the lead craniofacial surgeon in adult services at the Mater Misercordiae University Hospital or St. James's Hospital for on-going treatment and management.

In 2012, there was an increase in both clinical and surgical activity. Pre-operative nurse-led assessments were formalised by the addition of a craniofacial nurse specialist who joined the team in late 2011. Both the education of staff and the journey for the patient post-operatively have been enhanced by the introduction of care plans for specific craniofacial procedures.

Information dissemination is an integral part of rare diseases and the NPCC has set up a specific information website for parents and children to access information relevant to their individual condition at www.craniofacialireland.ie.

19.2 PROPOSED MODEL OF CARE

While recognising that adequate care can be provided outside of craniofacial centres, due to the complex nature of patients with craniofacial conditions, we strongly believe that optimal care is best accomplished by teams of interdisciplinary specialists who are dedicated to the care and management of patients with craniofacial anomalies and see a sufficient number of affected patients to understand the management complexities as outlined in Appendix 2 - Care Pathway for Syndromic/Non-Syndromic Craniosynostosis.

19.3 REQUIREMENTS FOR SUCCESSFUL IMPLEMENTATION OF MODEL OF CARE

Infrastructure	As it currently stands, the management of children with craniofacial conditions is undertaken between three sites, which makes the patients' journey somewhat less well defined. There is no doubt that a single hospital with all the appropriate specialties for the management of all paediatric patients is an absolute requirement, this will go a long way to improving the services for children with these rare conditions. Within this, there should be a seamless transition between, the clinics, the wards, and the operating theatre. Also, the various diagnostic and investigational procedures are a basic requirement for these patients. Within the outpatient department, multidisciplinary clinics in a large space, which is friendly, open and non-intimidating to these children, is something to aspire to in the new children's hospital. Technology is essential, in view of the complex reconstructions that are carried out and the planning of these reconstructions, which involves advance technology such as 3D modelling etc., this is now becoming the standard of care. This should be provided in the new children's hospital. Seamless flow of information between clinics, theatre and wards can only be facilitated through the appropriate electronic patient record. Similarly, a registry that allows access to the relevant patient records from the hospital is also a requirement.

Human Resources	**Consultant Team:** The core consultant team comprises one craniofacial/plastic surgeon and a neurosurgeon. This is supported by a maxillofacial surgeon with an interest in facial deformity. The NPCC is fully supported by the neurosurgical department to maintain the input of neurosurgery expertise and allows for cross-cover among neurosurgical colleagues. The present craniofacial surgeon is considered a high volume operator by other unit standards. This, together with the on-going expansion of services (e.g. facial palsy) will require a second craniofacial surgeon in the future to be appointed to the NPCC. *The addition of the following consultant specialities are also required:* *Orthodontist* Work in conjunction with the surgeons to monitor facial growth and to provide orthodontic treatment to optimise dental alignment and improve form and function. Dentofacial disproportion and malocclusions are a significant health burden in the craniofacial population. Patients are regularly referred to the MDT at St. James's Hospital for the assessment of growth disorders of the facial skeleton. In many cases, a two year course of decompensation orthodontics is followed by an orthognathic procedure (jaw surgery). There is currently no designated orthodontic specialist/ consultant to the craniofacial service. The service has expanded in terms of patient number as a result of the close alignment of the cleft and craniofacial services, but this has not been met with the appointment of additional staff. This has put severe pressure on the service. An additional orthodontic specialist in addition to the current complement of one consultant and a specialist is required to specifically treat cleft and craniofacial referrals from the Dublin Cleft Centre and the NPCC. *Prosthodontist* Provide oral rehabilitation, e.g. prosthodontic rehabilitation implants and periodontal care, which allows for the final stage of treatment, ensuring that each patient has the opportunity to have optimal results. Many patients with craniofacial disorders present early with hypodontia (missing teeth), heavily restored teeth and poor periodontal health. In many cases, the planning for the final oral rehabilitation begins as soon as the secondary dentition comes into place (6-12years). Whilst it is acknowledged that in most cases the formal prosthodontic treatment does not commence until late teenage years, it is vital that this service is available once the patients have been transitioned to adult services. A full time prosthodontist based at St. James's Hospital is recommended for those patients who transition from the cleft and craniofacial services at the new children's hospital. *Paediatric dentist* Currently, the craniofacial service has a 0.1 full time equivalent. Patients with craniofacial disorders regularly have complex dental issues from tooth decay and gum

disease to malocclusions (abnormal bite), including jaw disproportion which requires management from an early age. These conditions can influence the development of the teeth and bite (malocclusion) as well as the health of the gingiva (gums) and teeth themselves. It is vital that this very significant need is met at this early age in order to avoid future problems which make orthodontics and jaw surgery more complex. At present, patients depend on community services for their treatment. There are no preventative services available and in many cases this lack of prophylactic dentistry presents has resulted in patients presenting with rampant caries (decay) requiring a total dental clearance (removal of all teeth). This is a major priority for the craniofacial service. Whilst the availability of dental services are paramount, the craniofacial service does see this part of an overall improvement in the dental services for the hospital. This includes the cleft service and other medical specialities as well as on-call services.

Clinical Fellow

With over 60 transcranial index cases performed per year the NPCC is recognised as one of the largest craniofacial units in Europe. Being the only craniofacial unit in Ireland, and therefore receiving referrals from the 26 counties provides a very unique research opportunity. More recently, due to our international standing, there have been a significant number of enquiries from abroad to visit the unit both as observers and in fellowships. There is currently no funded fellowship programme in cleft and craniofacial surgery in Ireland. The development of this post is of paramount importance and will have significant benefits in terms of succession planning, international connections with other units, and maintaining the highest standards of surgical care of this cohort of patients. The research potential of the unit would also be maximised.

Craniofacial nurse specialist

There is one part-time clinical nurse specialist supporting the NPCC. The clinical nurse specialist plays an integral role in supporting and educating families and other health professionals both in-house and in the community. They also manage the child's journey from birth to eventual discharge from the service, including supporting their transition to adult services. This is a very time consuming, but undoubtedly well appreciated, aspect of the service provided by the NPCC, however this is at present under met. On-going expansion of services (e.g. facial palsy) will require 1.5–2 full time equivalent craniofacial nurse specialists / craniofacial advanced nurse practitioners.

Psychology

There is no dedicated psychologist associated with the service. Psychology input is accessed on an ad-hoc basis via the paediatric liaison team which cannot be depended on due to the pressure on the service. There is no doubt that a full time psychologist with a special interest in facial difference would contribute significantly to the patients' care. It is proposed that this psychologist could be appointed to patients with facial

difference from both cleft and craniofacial service as well as facial palsy and general plastic surgery (including burns and trauma). It is a serious concern that at the present time the only access to psychology services is often when young adults have developed adjustment disorders, low self-esteem, socialisation problems, and ultimately psychiatric disorders

Physiotherapy

The physiotherapist is a key specialist member of the NPCC. Currently, the craniofacial service is only one component of the workload of the plastics/musculoskeletal senior physiotherapist. The specialist physiotherapist is utilised as a resource for other physiotherapists nationally for consultation and treatment of more complex longstanding torticollis and plagiocephaly, as well as providing basic management of simple torticollis, positional plagiocephaly and neurodevelopment in the more complex syndromic synstotic conditions. An initial assessment, including a surgical consultation (for the craniofacial team) is performed. Leading from this, a conservative management plan or post-operative programme is devised and linked with community/local services as appropriate. More complex post-operative patients continue to attend Temple Street for an intensive physiotherapy programme.

The physiotherapist is also a core member of the facial palsy MDT. Roles include assessment, pre-operative assessment with photography, conservative management or preparation for patients for surgery and intensive post-operative treatment. Again, the physiotherapist is utilised as a learning resource for other physiotherapists nationally. As it is envisaged that expected growth in the facial palsy service will occur in the near future, the requirement for physiotherapy will increase to a significant extent, (as has occurred in many UK centres). The incidence of facial palsy is approx. 2/1000 live births (Children's Craniofacial Association, USA) and the annual live birth rate for the Republic of Ireland is 74,000 (CSO, 2011 data). Therefore, it is expected to see a maximum of 148 cases annually, of which, if only 5-10% required facial reanimation surgery, would total 8-15 major cases per year. An additional number would be smaller procedures, trauma and post-oncologic resection workload, for which there are no accurate data at this time.

From a research point of view, there is currently a dearth of research into the area of paediatric facial palsy, including physiotherapy interventions. While there is literature surrounding the management of positional plagiocephaly and torticollis, little is published regarding outcomes following torticollis release. The NPCC is optimally positioned to address these areas that warrant further study.
A whole-time clinical specialist physiotherapist is recommended to provide a quality service to both the craniofacial and facial palsy service, to act as a national learning resource, and to have an active role in research into the areas that are in urgent need of study.

Clinical photography

Photography, including 3D photography and video, is also considered standard care for patients, and forms part of the patient's record of care, particularly in patients with facial difference and facial palsy. This should be available for all clinics as well as pre-operative and post-operative records.

Clinical service manager

There is no doubt that this complex multidisciplinary speciality requires efficient and timely coordination. It would be expected that this would be provided by a full time clinical service manager. When the craniofacial services were initiated at Temple Street, a service manager appointed to both the cleft and craniofacial services was facilitated at 0.1WTE. As things have developed, the increased demand for the management of this service has been absorbed without any specific delineation or demarcation in the provision of the cleft or craniofacial service. The workload at the present time would support a full time manager to the service.

Speech and language therapy (SLT) services

The requirements for SLT services are wide ranging in the NPCC. Patients with craniofacial disorders often have delayed speech, or primary speech disorders related to their anatomy. Airway issues, and occasionally the management of severe trismus, will require the experience of a specialist SLT. The SLT also provides assessment and advice for children who require specialist speech, language and/or feeding assessments. Onward referrals are then made to local services for further management of communication or feeding impairments as needed.

With the development of the facial palsy MDT, a specific need has been identified in this cohort of patients where the management of specific speech disorders, electrical stimulation and post-operative therapy will complement the input from the physiotherapist. It is anticipated that there will be an increased need for SLT input for children in need of facial rehabilitation and/or who experience communication or feeding difficulties associated with facial palsy. SLTs are also involved in the provision of training and education of other therapists (including community therapists), undertaking research and audit, and liaising with therapy colleagues for cases. Therefore it is anticipated that further SLT resources will be needed for the NPCC as the service develops.

Occupational therapy

Referrals to occupational therapists for children with craniofacial conditions are most often captured under the other sub-specialties such as neurosurgery, plastics or respiratory depending on their diagnosis and needs.

Intervention is delivered depending on the individual patients needs in the areas of:

- Performance skills
- Equipment
- Discharge planning
- Community services

Genetics

Over 30% of craniofacial patients present with complex disorders with a genetic basis. It is estimated that there are 50-60 referrals to the genetic service each year. At present a genetic referral will take up to a year or more to be seen. This impacts significantly on the quality of the information that can be imparted to the already anxious and concerned parents. In many cases, family planning is difficult and more stressful due to the lack of information.

The appointment of a clinical geneticist to offer services to the surgical teams at Temple Street who deal with babies with birth defects is a priority. This includes:

- Plastic surgery (cleft and craniofacial and congenital limb malformation)
- Orthopaedic Surgery (osteogenesis imperfecta & skeletal dysplasias)
- Ophthalmology (anophthalmia, coloboma and retinal disorders - retinitis pigmentosa, cone dystrophies & retinoblastoma)
- ENT (sensori-neural hearing loss and microtia)
- Neurosurgery (neural tube defects and cerebral malformations)
- General surgery (tracheoesophageal fistula, gastroschisis, renal malformations)

Current (Temple Street)	Recommended
Craniofacial CNS - 0.8WTE	1WTE
Speech and Language Therapist - two sessions per month	1WTE
Physiotherapist - 0.5WTE to Plastics, Craniofacial and Hand Specialties	0.5WTE dedicated to Craniofacial
Dental - two clinic sessions and one theatre session per month	0.3WTE
Craniofacial services manager 0.1WTE	1WTE
Administrative assistant (appointment pending, June 2015)	

Specific Requirements in Education and Training

Clinical professionals need to ensure that they have the skills, competence and training to deliver a high quality service through continuous professional development, attendance at relevant training courses at national/international conferences. The craniofacial team regularly attends conferences and seminars along with benchmarking meetings which are currently either self-funded or funded through the fundraising department.

The craniofacial team is also involved in the education of both healthcare professionals and the public through a number of difference avenues, including lectures to various allied specialty groups (neonatology), teaching of graduate and undergraduate programmes through Dublin City University (DCU) and on-going seminars with regional maternity units. In terms of public education the website has recently been set up, and this together with the craniofacial family fun day provides families and parents with support and information.

Interdependencies with Other Clinical Programmes	Craniofacial surgery is a very complex multidisciplinary specialty which continuously interacts with other specialties including neurosurgery, ENT, hand specialist, ophthalmology, genetics, oral / maxillofacial surgery, dental orthodontics and prosthodontics. This interaction occurs both informally, and more formally at the specialist satellite clinics in St. James's Hospital and Crumlin. Future Developments: The potential to deliver an 'All-Ireland' craniofacial service is currently being discussed with consultant colleagues in Belfast. It is envisaged that the NPCC will provide a 'hub and spoke' model whereby satellite clinics could be facilitated in the Royal Children's Hospital in Belfast and surgical aspects of care in Temple Street. It is anticipated that the facial palsy service will grow significantly. Given that it is widely appreciated that at the present time a number of children are being treated in the United Kingdom (UK).

19.4 PROGRAMME METRICS AND EVALUATION

Clinical outcomes and clinical audits are integral part of the service provided by the national paediatric craniofacial centre. The NPCC through its craniofacial research group (CRG) regularly undertakes audits which are presented at both national and international meetings. A statistical analysis is presented to a UK clinical audit meeting on a yearly basis.

The NPCC has established research links with RCSI, UCD, DCU, and TCD and is involved in on-going research including investigating the molecular biology of bone in craniosynostosis and the design of novel medical devices.

There is a mentoring and support system in place to encourage and foster medical students, post-graduates, and surgeons in training, along with members of the MDT to undertake research and audit. Through the CRG the centre has received a number of awards including a major grant from the Child Fund for Health and the Healing Foundation (UK Charity). A list of publications by NPCC is detailed in Appendix 3.

19.5 KEY RECOMMENDATIONS

- Due to the complex nature of patients with craniofacial conditions, optimal care is best accomplished by teams of interdisciplinary specialists. The team will include surgeons (plastic/craniofacial, neursurgery, maxillofacial), orthodontist, prosthodontist, paediatric dentist, clinical nurse specialist, psychologist, physiotherapist, speech and language therapist, occupational therapist, clinical service manager, clinical photographer and geneticist.
- The service should be centralised within the new children's hospital with seamless transition of both patients and their clinical information between, the clinics, the wards, and the operating theatre. A registry that allows access to the relevant patient records from the hospital is also a requirement.
- A potential 'All-Ireland' craniofacial service is currently being discussed with consultant colleagues in Belfast. It is envisaged that the National Paediatric Craniofacial Centre will provide a 'hub and spoke' model whereby satellite clinics could be facilitated in the Royal Children's Hospital in Belfast and surgical aspects of care in Temple Street.
- Clinical outcome measurement and clinical audits should continue to be an integral part of the service.

19.6 ABBREVIATIONS AND ACRONYMS

CRG	Craniofacial Research Group
DCU	Dublin City University
MDT	Multidisciplinary Team
NPCC	National Paediatric Craniofacial Centre
OLCHC	Our Lady's Children's Hospital Crumlin
RCSI	Royal College of Surgeons of Ireland
TCD	Trinity College Dublin
TSCUH	Temple Street Children's University Hospital
UCD	University College Dublin
UK	United Kingdom

19.7 REFERENCES

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19.8 APPENDICES

19.8.1 Appendix 1 Surgical Procedures

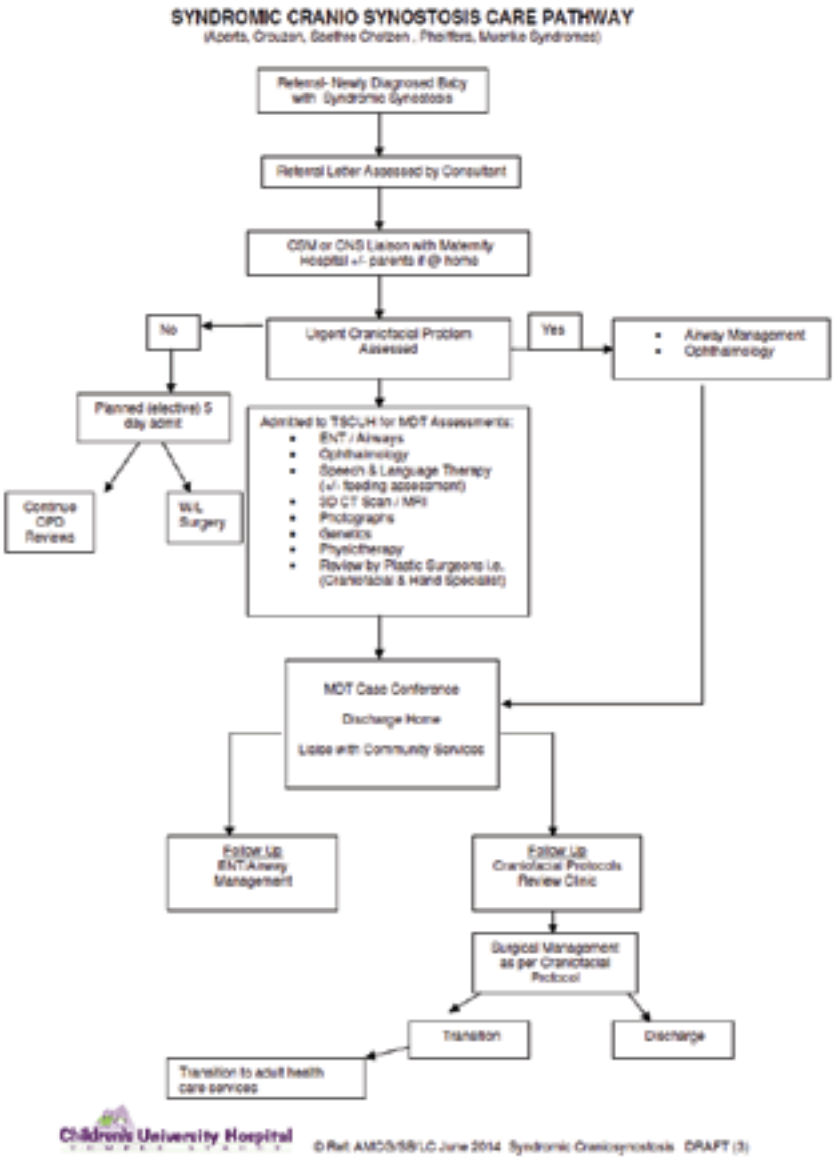
Craniosynostosis

Surgical conditions treated:

Non-Syndromic		Syndromic
Sagittal Synostosis (<6 months)	SS	Aperts
Sagittal Synostosis (>6 months)	SS	Crouzons
Metopic Synostosis MS		Saethre Chotzen
Unicoronal Craniosynostosis RUC / LUC	(Rt / Lt)	Pfeiffers
Bicoronal Synostosis	BC	Muenke
Lambdoid Synostosis	LS	
Multiple Suture Synostosis	MSC	

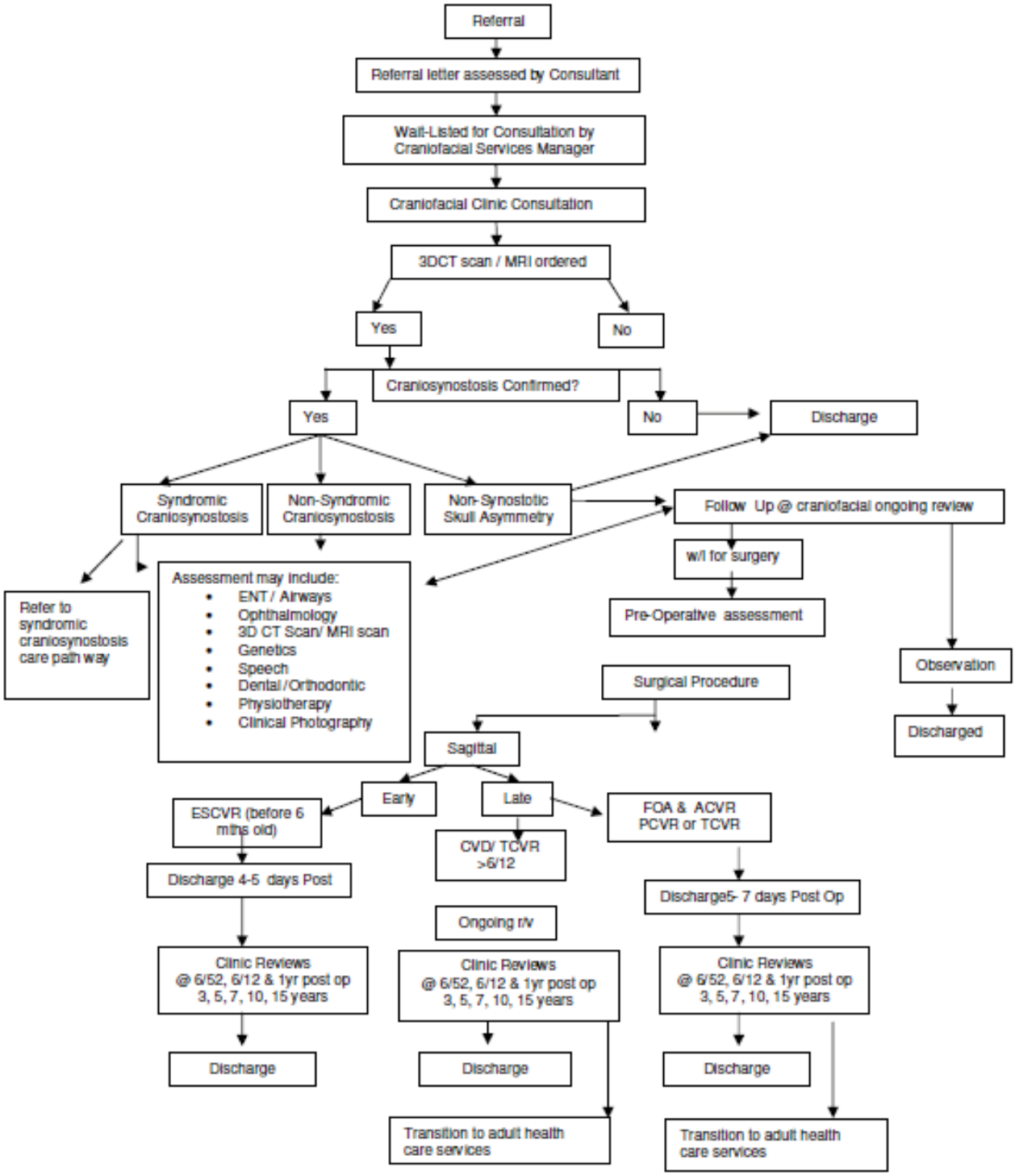
Cranial Vault Procedures	Facial Procedures
Extended Strip Craniectomy (ESCVR)	Midface Advancement (Lefort III)
Cranial Vault Distraction (CVD)	Midface Distraction (RED distraction) (LeFort Distraction)
Fronto Orbital Advancement (FOA)	Mandibular distraction
Anterior Cranial Vault Remodelling (ACVR)	Orthognathic Surgery • Lefort I • Sagittal Split osteotomy (BSSO) • Surgically assisted palatal expansion (SARPE)
Posterior Cranial Vault Remodelling (Expansion) (PCVR)	
Posterior Cranial Vault Distraction (PCVD)	
Total Cranial Vault Remodelling (TCVR)	

19.8.2 Appendix 2 Care Pathways for Syndromic and Non-Syndromic Synostosis



NON – SYNDROMIC CRANIO SYNOSTOSIS CARE PATHWAY

(Saggital Synostosis, Metopic Synostosis, Unicoronal Synostosis, Bi-coronal Synostosis, Lambold Synostosis, Multiple suture Synostosis)



Children's University Hospital

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19.8.3 Appendix 3 Publications

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IMJ 2014 Nov/Dec Vol 107 No. 10

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IMJ 2014 Nov/Dec Vol 107 No. 10

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