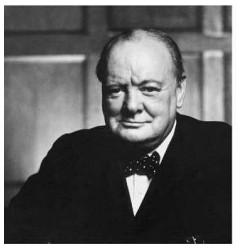
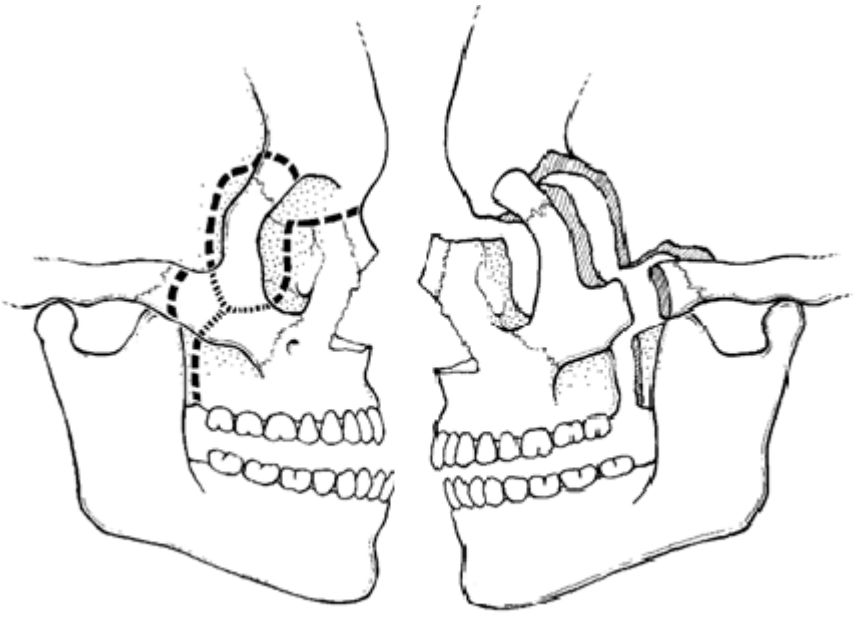


WINSTON CHURCHILL MEMORIAL TRUST

Improving Outcomes of Surgery in Patients with

FACIAL DEFORMITY



Allan Ponniah

Churchill Fellow 2015

CONTENTS

1. ACKNOWLEDGEMENTS

I am grateful to the Winston Churchill Memorial Trust for giving me the opportunity to embark on this life changing Fellowship. My thanks go out to this great organization and the inspiring and helpful staff, also to previous Fellows for showing me what was possible. I would also like to thank the British Association of Plastic Reconstructive and Aesthetic Surgeons for the Travelling Bursary which allowed me to extend my time at Erasmus MC and to the Honorable Jill Ganzoni for her support for this Fellowship and throughout my career.

I would like to extend my thanks to Mr David Dunaway, the clinical lead of the Craniofacial department at Great Ormond Street Hospital for Children. David first introduced me to the fascinating world of Craniofacial surgery 10 years ago and has been my mentor and friend throughout.

During my Fellowship, I met some great people and new friends. I would like to thank all the team at Erasmus MC especially Professor Irene Mathijssen who warmly welcomed me into the team and taught me a great amount regarding the management of patients with facial deformity and a variety of surgical techniques. I would also like to thank Dr Eric Arnaud, the head of the Craniofacial department at Necker Children's Hospital in Paris and Dr Yoshiaki Sakamoto from Keio University, Tokyo.

WINSTON CHURCHILL MEMORIAL TRUST

BAPRAS
British Association of Plastic Reconstructive and Aesthetic Surgeons

2. GLOSSARY

Apert syndrome – A genetic disorder where there is abnormal fusion of skull, face and hand bones.

Cerebellar tonsils – part of the brain which can push down the spinal canal in syndromic craniosynostosis

Chiari I malformation – crowding inside the skull that causes the cerebellar tonsils to be pushed down the spinal canal

Cranial vault – the space in the skull where the brain is

Craniofrontonasal dysplasia – rare syndrome caused by a genetic mutation where the eyes are abnormally apart, the nose is split and there is premature fusion of skull bones

Cranioplasty – surgical repair of a defect or deformity of the skull

Craniosynostosis – abnormal fusion of two or more skull bones

Crouzon syndrome – a genetic disorder where there is premature fusion of skull and face bones

Distraction – a process which increases the size of bones by creating a fracture and slowly pulling the parts apart

Frontoorbital remodeling – surgery to correct abnormalities in the shape of the bones of the forehead

Hydrocephalus – abnormal accumulation of fluid in the brain

Hypertelorism – where the eyes are too far apart

Internal distraction – distraction when the devices are under the skin

Intracranial – inside the part of the skull which contains the brain

Metopic synostosis – premature fusion of the of the bony join in the middle of the forehead

Monobloc distraction – an operation which treats syndromic craniosynostosis by advancing the bony part of the face that is underdeveloped

Obstructive sleep apnoea – a condition where the wall of the throat narrow during sleep causing an interruption to normal breathing

Osteotomies – surgical cuts in bones

Pfeiffer syndrome - a genetic disorder with premature fusion of skull bones and large thumbs

Sagittal synostosis – premature fusion of the join that runs along the top of the skull

Shunt – a tube which takes excess fluid away from the brain

Spinal canal – a cavity down the middle of the spine

Supraorbital – bony part above the eye

Syndromic craniosynostosis –premature fusion of joins in the skull and a collection of abnormalities

Temporal hollowing – concavity at the temples

Transfacial pin – a wire drill through the cheek bones across the face

Unicoronal synostosis – abnormal fusion of bones on one side of the forehead

3. EXECUTIVE SUMMARY

I am a British trained plastic and reconstructive surgeon with a special interest in craniofacial surgery. I recently completed my training and am looking to further develop my career within the field of craniofacial surgery. Much of the research and clinical work in craniofacial surgery I have done in the past has been at Great Ormond Street Hospital in London.

Craniofacial deformity can have a profound effect on those who suffer from it and those around them. It not only affects appearance, but also functions such as vision, eating, speaking, hearing, cognitive development and socialization. Having dedicated several years of my life to treating children born with these problems, I was very grateful to be given the opportunity to travel to Holland, France and Japan to understand ways in which outcomes of surgery for these patients could be improved.

The majority of my Fellowship was spent at Erasmus MC in Rotterdam, which is the only hospital in the whole of Holland that performs the complex craniofacial reconstructions required in syndromic craniosynostosis. Within Erasmus MC, most of these operations are performed at the Sofia Children's Hospital. I also visited Tokyo and Paris. Paris is where the discipline of craniofacial surgery started at the hand of Dr Paul Tessier. My Fellowship was a combination of learning how to perform new craniofacial procedures and learning how these cases were managed in different countries. I also initiated some research collaborations which aim to further the treatment of those affected.

The key potential improvements I identified:

1. Early diagnosis – it is possible to diagnose some of these conditions prenatally
2. Correct initial management – early management can impact late outcome
3. Correct referral pathway – referral to the correct team is critical
4. Monitoring in the outpatient setting – simple outpatient measurements are useful
5. Patient pathways – differences between countries should be studied and learned from
6. Managing complex cases – key differences show ways things could be improved
7. Surgical techniques – different techniques and how they could be applied in the UK
8. Surgical outcomes - measuring outcomes can help identify the best operations
9. Longterm followup – lengthening followup in the UK can identify longterm issues

4. RECOMMENDATIONS SUMMARY

1. Education at the 20 week scan level to increase the early diagnosis of single suture craniosynostosis
2. Education to allow correct positioning of patients with Scaphocephaly
3. Improving the referral pathway in the UK to the highly specialised centres
4. Measuring skull growth in the outpatient setting
5. Comparing patient pathways between units to identify potential improvements
6. Compare cohorts that are managed in different ways to understand differences in outcomes
7. Identify potential new surgical techniques which can be used at GOSH
8. Evaluate patient outcomes using objective tool to compare different techniques
9. Set up long term follow up clinics to identify long term outcomes of single suture surgery

5. INTRODUCTION

5.1 Background

The Winston Churchill Memorial Trust[1] was set up in 1965 as a living memorial to Winston Churchill a great politician, innovator, artist and traveler with a love for life and who was voted the greatest Briton of all time. It has been designed to offer citizens of Great Britain life changing opportunities to travel and bring back to the UK fresh and new ideas to improve the lives of people in the UK. The Trust funds a wide range of projects including categories such as education, horticulture and designers. In 2015 I had the fortune of being awarded a Churchill Fellowship in the Medicine, Health & Patient Care category.

I have recently completed my training as a plastic surgeon and my main passion is craniofacial surgery. This is the treatment of children and adults born with facial and skull deformities. It is the aim of treating these patients that they are given the opportunity to live as normal a life as possible. There are many factors to consider when treating these patients therefore usually a large team of professionals are required including surgeons, nurses, anaesthetists, psychologists, speech and language therapists, ophthalmologists, radiologists and geneticists. One of the commonly treated conditions is craniosynostosis which has an estimated global incidence of 1 in 2000 live births[2]. The majority of cases are the simple form which affects skull shape; more severe forms can affect the face and hands. In the more severe forms the key issues are that there is undergrowth of the skull and facial bones which can cause pressure on the brain, inadequate eye protection and difficulties with breathing. Surgery can improve many of the problems that these children face, but can still leave patients with stigmata of facial deformity. As a surgeon, my aim is to develop techniques to remove all stigmata of facial deformity.

Following my passion has led me to research how the faces of patients with facial deformity differ from the rest of the population. This research over the last 10 years has mainly been with David Dunaway the head of the Craniofacial Unit at Great Ormond Street Hospital for children[3] in London. In 2012 I set up "Mein3D" at the London Science Museum which collected the largest number of 3D facial scans from a population that contained all age groups, all ethnicities and both genders. Having coordinated collaboration with I-BUG of Imperial College London[4] and using one of the first automated landmarking systems and cutting edge technology, we have created a mathematical model of normal facial variation. I plan to develop this model so that outcomes of surgery can be assessed and new techniques devised. In the recent congress of the International Society of Craniofacial Surgery in Tokyo, Japan[5], I was author or co-author on 13 papers presented and approached by some of the world's top craniofacial surgeons to enter into collaborative work on the assessment and development of new techniques in craniofacial surgery

In fields such as craniofacial surgery, it is important that surgeons visit other units around the world. This is because as it is such a small specialty, the number of cases seen per year is relatively low and it important to keep up to date with new techniques and fully understand the care and after care in

different settings. It is also useful for surgeons to spend a few months concentrating their efforts and energy on craniofacial surgery without extra clinical commitments such as oncalls, emergency work etc. Visiting other units allows unique perspectives on how to manage these patients and comparing and contrasting them with one's own practice gives one a far broader understanding of the subject. It also enables collaboration and pooling of patient data which is vital for research into these rare conditions.

During the course of my Fellowship I noticed that there were multiple factors involved in treating these patients and that surgery was only part of the puzzle. In this report I aim to systematically review many of the main factors that are involved in improving outcomes, acknowledging that this is not an exhaustive list.

5.2 Aims and Objectives

The purpose of my Fellowship was to gain clinical and surgical experience in the management of craniofacial conditions outside the UK. I also wanted to set up collaborative research projects with the aim of assessing and improving the outcomes of craniofacial surgery.

5.3 Methods and Itinerary

I was funded for a 3 month Fellowship which was mainly to visit the Craniofacial Unit at Erasmus MC[6] in Rotterdam, Holland. During this period I had the opportunity to visit Necker Childrens Hospital[7] in Paris and to attend and present at the congress of the International Society of Craniofacial Surgery in Tokyo, Japan. Funding from the British Association of Plastic Surgeons allowed for a further 2 months in Rotterdam.

Why Rotterdam?

The Craniofacial Unit at Erasmus MC in Rotterdam offers specialist care for patients from all over Holland. This model of centralization allows for expertise to be gained in managing these rare and complex conditions. The majority of my report will be referring to the experience and knowledge gained in Rotterdam. Extensive research into craniofacial conditions is carried out at the Unit headed by Professor Irene Mathijssen. This part of the Fellowship allowed hands on experience and training in craniofacial surgery as well as the opportunity for research. I was very interested to set up collaborative work and to further develop the connection between Erasmus MC and Great Ormond Street Hospital. As Erasmus MC caters for many different specialities and subspecialties, I was also able to get involved in head and neck reconstruction, maxillofacial surgery and microsurgery, all of which I believe will play a role in the future of craniofacial surgery.

A photo Sofia Children's Hospital

A photo outside the hospital entrance

Outside the maxfax department

Why Paris?

Paul Tessier the father of craniofacial surgery and the founding member of the International Society of Craniofacial Surgery developed many of the techniques used today. His legacy lived on through the late Daniel Marchac his successor and the current Head of department at Necker Children's Hospital, Eric Arnaud. I was interested to see how surgery was currently performed at Necker to see if I could see echoes of Paul Tessier's work and how things have developed recently. I was particularly interested in their surgical technique of internal distraction.

Left:
Dr Eric Arnaud
Head of
Craniofacial
Surgery

Right:
Allan Ponniah
Fellow

A photo outside theatres at Necker Hospital

Left:
Allan Ponniah
Fellow

Right:
Roman Khonsari
Maxillofacial
Surgeon

A photo in the gardens of Necker Hospital

Why Japan?

In 2015 the congress of the International Society of Craniofacial Surgery was in Tokyo, Japan. This is a fantastic opportunity to present research and learn of all the latest advances in craniofacial surgery. It is also a great place to set up collaborative work with people who are carrying out similar research. During my trip to Japan I also got the opportunity to visit a surgeon who has a different technique of internal distraction[8].

Presenting my research in Tokyo, Japan

5.5 Report overview

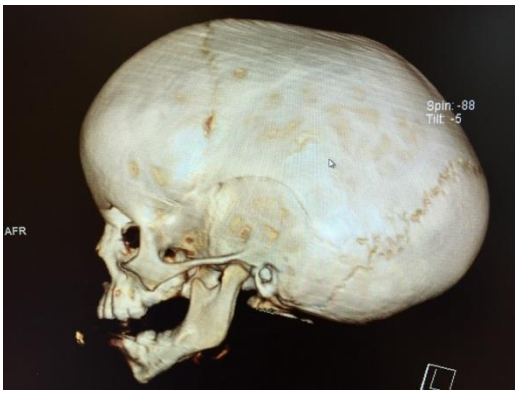
Having noticed that there are multiple factors which influence the outcomes of treatment of these patients, I decided to break my report into the following headings:

1. Early diagnosis
2. Correct initial management
3. Correct referral pathway
4. Monitoring in the outpatient setting
5. Patient pathways
6. Managing complex cases
7. Surgical techniques
8. Surgical outcomes
9. Longterm followup

6. FINDINGS

6.1 Early diagnosis

There are many aspects to early diagnosis, but I would like to elaborate on one of the aspects I learned at Erasmus MC. Single suture craniosynostosis such as sagittal synostosis (elongated head) and metopic synostosis (triangular forehead) cause abnormalities in the skull shape and are not routinely picked up prenatally. Retrospective research carried out at Erasmus identified affected patients and looked at their prenatal scans to see if the diagnosis could have been made before birth. To a trained eye it would have been possible to diagnose these conditions at the 20 week scan. This has vast implications, because if the diagnosis is picked up prenatally, treatment can be initiated immediately after birth (see next section) in the sagittal synostosis cohort. It could also allow for early counselling of the parents so they can understand what to expect, and be advised on how to look after their child and at what age treatment may be necessary. In order for benefit to be realized from these studies, awareness needs to be increased among those who perform the 20 week scan and amongst the general public. Further collaborative work with imaging and genetics research may lead to other techniques of early diagnosis.



Skull CT scan of a patient with sagittal synostosis

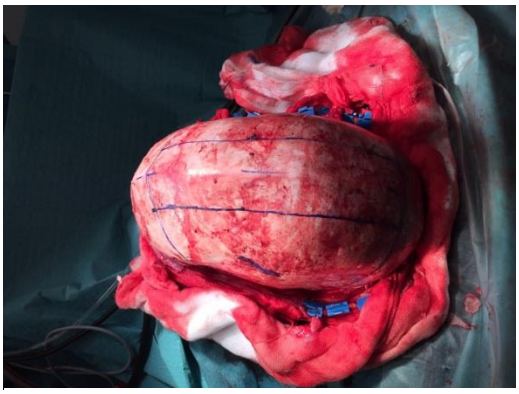


Photo of same patient during surgery

6.2 Correct initial management

In the case of sagittal synostosis there have been studies that suggest early surgery can improve long term neurodevelopmental function[9]. This would suggest that early diagnosis is important. In terms of early treatment, at Erasmus MC it has been shown that simple measures taken by the parents initially can have dramatic effects. They demonstrated that if the parents were taught how to position their babies prior to sleep with them lying on the back of their head, this actually affected the shape of their head. It is therefore possible to reduce the elongation of the head with this simple method. In mild cases this may mean that no surgery is required and in the cases that require surgery this may mean the final result could be improved. More work is required to verify this, but as it is

such a simple technique, it should certainly be taught to parents, who if they chose to could be involved in further research.

6.3 Correct referral pathway

As these patients have complex problems, it seems likely that they would be best looked after in centres with expertise who see many similar cases. Having said this, in many parts of the world including the US the services are fragmented. In the UK and Holland it has been recognised that these patients require specialist expertise and therefore care as been centralised to a few units. Patients and families in specialist units get access to other families with similar conditions and the wealth of expertise and facilities that are concentrated and specifically set up for their needs. In the UK there is an annual audit meeting where difficult cases can be discussed and problems at any of the units can be addressed with the combined expertise for the fours units. This set up also allows government spending to be focused on these centres allowing for things such as the latest necessary specialist equipment to be purchased. In Holland, craniofacial services are generally focussed around Erasmus MC. I have witnessed cases where the treatment was initially carried out in centres less well equipped who found difficulties in managing the complexity of these cases therefore care had to be transferred to Erasmus MC for continued care. It is therefore important to raise awareness of the best pathway for these children. Professor Mathijssen has recently published guidelines[10] which detail optimum management pathways based on a review of the scientific evidence in the literature, and experience from; The Dutch National Cranial and Facial Deformities Patients and Parents Association, The Netherlands Society for Ophthalmology, The Netherlands Society for Anesthiology, The Netherlands Society Otorhinolaryngology, The Dutch Association for Pediatrics, The Netherlands Society for Oral Medicine and Oral and Maxillofacial Surgery, The Netherlands Society for Neurosurgery, The Netherlands Society for Plastic Surgery, The Society for Orthodontists, The Netherlands Society for Clinical Genetics, The Dutch Association of Psychologists, The Netherlands Society for Relationship Counseling and Family Therapy. I think it is important to work with the wealth of experience and knowledge that has been amassed by the Dutch teams and summarised into a guideline to see if there are any aspects that would benefit patients in the UK. The aspects which I am most interested in understanding are the referral pathways as it appears that many patients are referred too late and in some cases not at all. I think it would be useful to address the referral pathway in the UK first, then look at the other aspects of the patient pathway as detailed in the guideline. The recommendations as to how to optimise recognition of craniosynostosis are as follows:

1. Ensure that easily accessible, reliable, and unambiguous information is available about skull deformities, either as appendix to this guideline, or via separate guidelines; preferably with many illustrations, clear terminology/definitions and addresses.
2. Ensure that the flow diagram (Appendix) is used.
3. Provide structured education and training instruction to infant health center physicians, GPs, midwives and obstetricians about over skull deformities via centers of expertise with an initiating

role for the tertiary centers.
4. Provide feedback about the referral pattern on the basis of an analysis of national registry data (focus on patient's age at referral to tertiary center).

It also includes advise on patient information in the form of website information for patients, primary and secondary providers. In the UK the servicing are mainly focussed around four units: Great Ormond street Hospital in London, John Radcliffe hospital in Oxford, Alder Hey in Liverpool and Birmingham Children's Hospital. In order to raise awareness among the general public and referrers, on speaking with NHS England, I am involved in setting up a website which is designed to educate its visitors on the best pathway to get the best outcome of treatment. This website could be developed into an interactive tool which initially guides patients to the correct services at the correct time.

6.4 Monitoring head growth in the outpatient setting

As many of the cases of craniosynostosis result in abnormal head shape and abnormal head growth, it is important to monitor growth in the outpatient setting. This is particularly important as if the head grows too slowly, the brain may have too much pressure exerted on it which can affect the childs development, vision, function and in worst cases can cause death. Early detection is vital and at Erasmus MC they have studied the correlation between the head circumference and intracranial volume. They have demonstrated that routinely measuring head circumference and tracking growth is a good way to detect early changes[11] and also a good way to put parents minds at ease when everything is progressing well. They therefore advocate measuring head circumference and plotting it at each clinic visit. When the growth begins to slow, this may be an early sign that the child is at risk of raised intracranial pressure. This then needs to be further investigated so the correct course of action can be taken.

A patient having their head circumference measured

6.5 Patient pathways

Having been the Craniofacial Fellow at Great Ormond Street Hospital for Children from 2014-2015 I was familiar with the patient pathways used at GOSH. I was interested to note that there were differences in the pathways followed at Erasmus. It would be great to be able to compare outcomes between these 2 centres to see if different protocols lead to different results. The results of this research could be the basis of the design for the next generation in patient pathways.

6.6 Managing complex cases

Seeing a different perspective in managing complex cases was refreshing, and although there were many similarities, I would like to discuss some of the differences, specifically the management of obstructive sleep apnoea, shunts, and chiari malformations.

Obstructive sleep apnoea

Patients with syndromic craniosynostosis have a high prevalence of obstructive sleep apnoea. This can occur at multiple levels and therefore a protocol has been established at Erasmus where patients undergo endoscopy of the upper airways at the time of their first surgery[12]. This allows identification of the level of the obstruction and can therefore give a clue as to what would be the best treatment to alleviate the obstruction. There is no conclusive evidence yet as to the amount of benefit to OSA obtained through midface advancement. If it was know that there were other levels of obstruction in patients undergoing midface surgery other than at the midface level, these could be excluded from such studies therefore allowing for a definitive answer. As these numbers are likely to be low, it is important that data is pooled from craniofacial centres such as Erasmus MC, Necker Hospital and Great Ormond Street and if possible others.

VP shunts

When patients have hydrocephalus (extra fluid in the brain) it can cause an increase in the intracranial pressure. A typical solution is to place a VP-shunt which is a tube with a valve that diverts the fluid into the abdominal cavity. At Rotterdam, the philosophy is that shunts should be a last resort as they are thought to be counterproductive to cranial expansion. In the first instance a cranial vault expansion is favoured, and even in the second instance. A shunt is chosen as a last resort following optimum cranial vault expansions. This is a different philosophy to that in the UK and it would be very interesting to compare results. If it is possible to reduce the number of shunts placed without compromising care, this would be of great benefit as the potential complications of shunts can be catastrophic.

Chiari I Malformation

This can occur in craniosynostosis and appears to be most common in Crouzon/Pfeiffer syndrome [13] . It is when there is downward displacement of the cerebellar tonsills through the foramen

magnum. There is a lot of disagreement in the literature regarding definition and treatment. It is therefore important for multicentre studies to be set up to achieve definitive answers. Decompression for this condition is rarely done at Erasmus MC, however it has been done on occasion at GOSH. It would be interesting to compare the patient cohorts to identify possible reasons for these differences and clarify best treatment protocol.

6.7 Surgical techniques

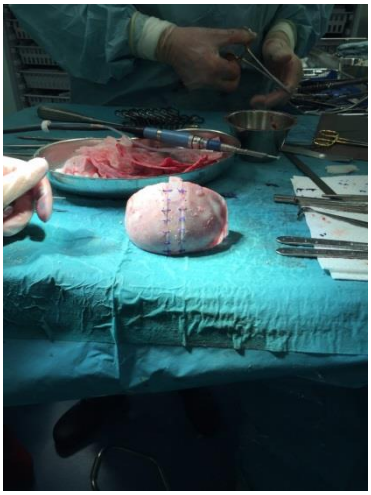
Many aspects of the surgical techniques are similar; I am going to briefly describe some differences I noted between GOSH and the european centres.

Spring cranioplasty

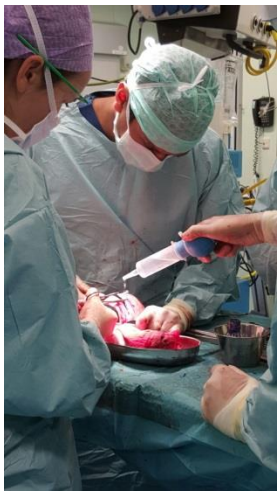
Both units use the same type of springs. The difference lie in the osteotomies made and the placement of springs. At GOSH the osteotomies are made 2 cm from the midline and at Erasmus 4cm from the midline. At GOSH 6cm springs are used and at Erasmus 9cm springs are used. It would be interesting to compare the two cohorts to see if one technique is better than the other.

Frontoorbital remodeling

This is performed typically for single suture craniosynostosis such as metopic craniosynostosis and unicoronal craniosynostosis. The differences between GOSH and Erasmus are mainly around the technique used. At Erasmus the technique involved a supraorbital bar as the basis of the reconstruction whereas at GOSH the forehead is taken off higher as a single piece which is split in the midline and refashioned. At GOSH metal wires are used to secure the reconstruction and any metal work has the potential to extrude. At Erasmus the bone is secured with Vicryl which therefore reduces the risk of metal extrusion.



A remodeled forehead during surgery



A photo of me performing surgery

Midface advancement

In Rotterdam

For monobloc distraction, osteotomies are made in a similar way to at GOSH. The temporal muscle is fully stripped from the bone to allow for placement of internal distractors. The internal distraction protocol involves a distraction period and then a consolidation period where they are leave in place for around 4 months. In the very young a transfacial pin is used to ensure that the whole monobloc segment advances forward together.

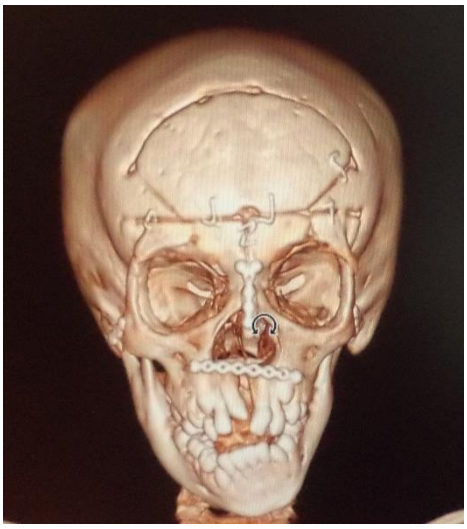
In Japan

For monobloc distraction, again similar osteotomies are made. The distraction devices are different in design[8], but the placement and vectors of distraction are similar.

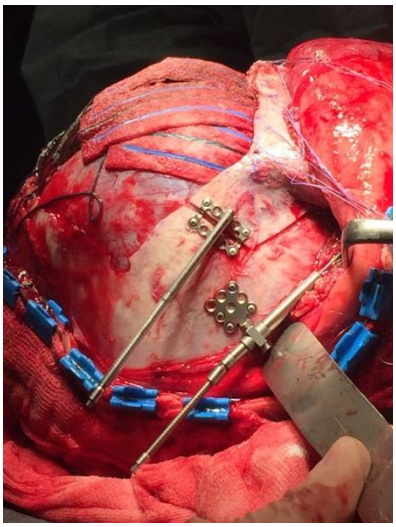
In Paris

Here the technique used is very similar to that in Rotterdam.

Having experienced a number of different ways of performing this procedure, I have developed a much broader understanding of how the forces affect the changes in facial shape. The other techniques I learned in Paris included correction of hypertelorism which can be seen the photo below.



A scan of a patient after hypertelorism correction



Internal distractors during Monobloc surgery

6.8 Surgical outcomes

It is becoming increasingly important to measure surgical outcomes and it has been said that "Outcome measurement is the single most important tool to drive innovation in health care delivery"[14]. My research looking at 10 000 normal faces from the London Science Museum has led to the creation of an outcome measurement tool. This tool is in its infancy, but if tested in different centres around the world can be refined till it can be a valuable resource. The tool itself was designed to measure the amount of improvement in face shape achieved through surgical intervention. This tool should be seen in the context of the overall outcome of patient care. Outcome measurements are key in allowing comparisons of outcomes within departments and between departments. Below is an example of the tool in action, the tool takes the whole face shape and measures it against the reference population of 10 000, 2 standard deviations away from the mean are set as 1 so that if a patient scores a value of 1 they are within the normal range and if it is above 1 they are out of the normal range. Ideally surgery would bring the score down to 1.

In Rotterdam to begin testing of this tool we have chosen a specific subset of patients with Craniofrontonasal dysplasia. This is a condition which leads to the distance between the eyes being far greater than normal, which is also known as hypertelorism. Surgery moves the bony eye sockets closer together. The study aims to evaluate scans before and after surgery of the patients using the outcome assessment tool, and to compare this with subjective assessments to validate the objective scoring system. If this project works well, the process can be repeated for other conditions.

In Paris I set up a collaborative research project which aims to look at the longterm outcomes of patients who have surgery for syndromic craniosynostosis. They have CT scans at various points throughout there treatment and at each point, we can measure how far they are away from the normal. The hope is that throughout their treatment they continue to progress further towards and hopefully within the normal range. The study will be the first objective way of measuring this and

will allow the comparison of techniques in Paris (internal distraction) with techniques at GOSH (external distraction).

Potential future collaborative work would be to trial the system in other countries around the world and there has been interest from Richard Hopper in Seattle and Jeffrey Fearon in Dallas. If the system is deemed to be accurate it could become the gold standard for measuring outcomes and could be very useful in identifying which techniques are best for the patients and be the basis to design new surgical techniques.

6.9 Longterm followup

Typically at Great Ormond Street Hospital for single suture craniosynostosis followup is carried out up to the age of 7 years. This is to ensure that there are no problems with raised intracranial pressure as the likelihood of a child developing such problems after this age are pretty low. Interestingly, at Erasmus MC follow up is until 18 years of age. This is to ensure there is no relapse or problems with the shape of the skull as the child reaches adulthood. Having attended clinics where patients are seen many years after surgery, it was very useful to understand potential problems that could occur such as late onset temporal hollowing. These cases are seen in the UK when patients come back because they have concerns, however there may be many patients who are unaware that anything could be done, so they do not return. Extending clinics beyond 7 years maybe something worth considering.

7. CONCLUSIONS

I have thoroughly enjoyed this Fellowship and learned many things that I hope to bring back to the UK. Erasmus MC has a lot to offer beyond craniofacial surgery also as it covers all aspects of plastic and reconstructive surgery therefore I can thoroughly recommend it as a Fellowship. I have learned a lot about clinical care and different surgical techniques and hope this is the beginning of many collaborative projects. In terms of improving outcomes, I have identified 9 areas which could be improved and therefore which could help children affected by these conditions in the UK.

8. RECOMMENDATIONS

1. Education at the 20 week scan level to increase the early diagnosis of single suture craniosynostosis

   This will involve liaising with ultrasonographers responsible for early scans to assess the feasibility of training to allow for early recognition. In the research group at GOSH, we are currently looking into the possibility of automated diagnosis of 3D ultrasound scans as these will become more readily available in the future.

2. Education to allow correct positioning of patients with Scaphocephaly

   Having discussed this with the specialist nurses at Great Ormond Street Hospital, new referrals will be given the appropriate advice and education. It is perhaps also important to have a national campaign to raise awareness in the general public.

3. Improving the referral pathway in the UK to the highly specialised centres

   In order to increase the public awareness of the highly specialised centres I have recently launched www.craniofacialuk.com. This is a platform which when developed can be a great educational resource which informs referral pathways.

4. Measuring skull growth in the outpatient setting

   I have introduced the concept of measuring skull growth by circumference at GOSH and this can be expanded to other units.

5. Comparing patient pathways between units to identify potential improvements

   Recently the Craniofacial team from Rotterdam visited GOSH to set up collaborative research work to look at the differences and similarities between the two approaches. This work can then be extended to other units.

6. Compare cohorts that are managed in different ways to understand differences in outcomes

   Collaborative research has been set up between GOSH, Rotterdam and Paris and data is being collected to compare the differences in outcomes. I am currently working on refining the software required to compare these outcomes.

7. Identify potential new surgical techniques which can be used at GOSH

   As the collaborative research project grows more units from around the world will become involved. Units from places such as USA, Canada and Japan have expressed interest in becoming involved. Sharing information can lead to identification of which techniques work best around the world.

8. Evaluate patient outcomes using objective tool to compare different techniques

   This is the software tool which I am currently working on. The technology behind it is being published in the International Journal of Computer vision in 2016.

9. Set up long term follow up clinics to identify long term outcomes of single suture surgery

   This is currently being set up at GOSH in order to assess outcomes of previous patients and if successful can be taken forward prospectively.

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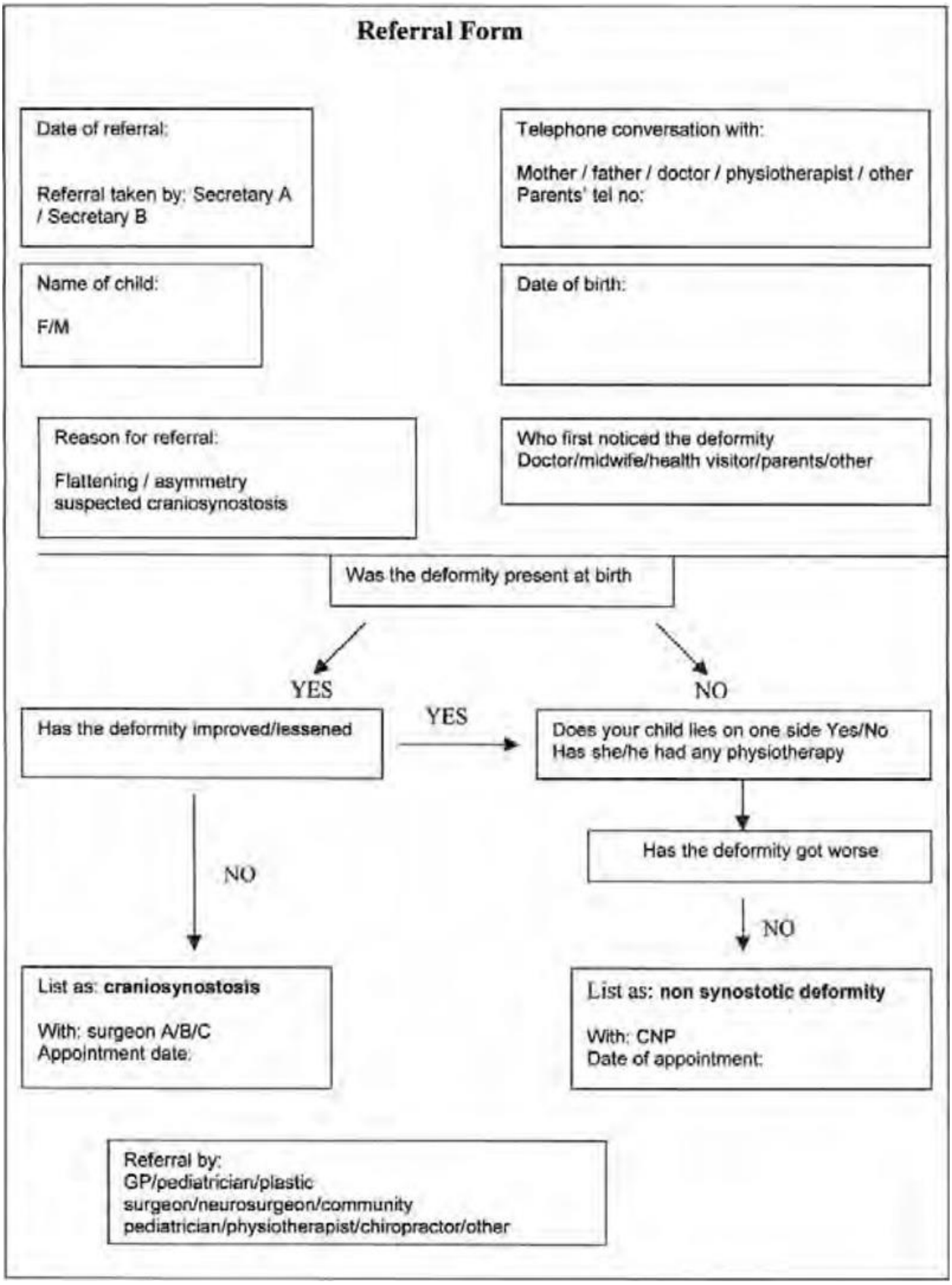
10. APPENDIX


Referral Form
Date of referral:
Referral taken by: Secretary A / Secretary B
Telephone conversation with:
Mother / father / doctor / physiotherapist / other
Parents' tel no:
Name of child:
F/M
Date of birth:
Reason for referral:
Flattening / asymmetry
suspected craniosynostosis
Who first noticed the deformity
Doctor/midwife/health visitor/parents/other
Was the deformity present at birth
YES
NO
Has the deformity improved/lessened
YES
Does your child lies on one side Yes/No
Has she/he had any physiotherapy
NO
Has the deformity got worse
NO
List as: craniosynostosis
With: surgeon A/B/C
Appointment date:
List as: non synostotic deformity
With: CNP
Date of appointment:
Referral by:
GP/pediatrician/plastic surgeon/neurosurgeon/community pediatrician/physiotherapist/chiropractor/other