CRANIOFACIAL SOCIETY ANNUAL MEETING, BRISTOL APRIL 2012

Abstracts and Posters

Thursday Abstracts / **Friday Abstracts** / **Posters**

Posters

The Incidence of Dental Anomalies in Patients with an Isolated Cleft Lip
Jennifer Vesey

Background: Some patients with clefting have an increased number of dental anomalies. However, there has been little research on the prevalence of dental anomalies in patients with an isolated cleft lip only. This study aimed to investigate the prevalence of dental anomalies in a group of patients born with an isolated cleft lip only.

Method: A retrospective cohort sample of 28 patients with an isolated cleft lip only who attended the South West Cleft Unit for routine follow up had their records assessed by two examiners for the presence of dental anomalies including; supernumerary teeth, hypodontia, microdontia and fused teeth. The results were described using quantitative statistics, with examiner reliability assessed using kappa statistics.

Results: The overall prevalence of dental anomalies was 42.9%. Supernumerary teeth were the most frequently occurring anomaly (prevalence 25.0%). The intra-examiner reliability was found to be perfect, ($\kappa = 1.00$), for all anomalies except hypodontia, which was substantial, ($\kappa = 0.62$). The inter-examiner reliability was found to be perfect, ($\kappa = 1.00$).

Conclusions: There is an increased prevalence of dental anomalies in patients with an isolated cleft lip only, with supernumerary teeth the most prevalent. Anomalies affected both the primary and secondary dentitions. Careful monitoring of the dental development of patients with isolated cleft lip should be undertaken.

The Introduction of Independent Non-Medical Prescribing (NMP) in the North West, Isle of Man and North Wales Cleft Network
Jennifer Williams, Helen Robson, Trisha Bannister

Introduction: The CNS team provides an autonomous nursing service across a wide geographical area. Children and families are managed at home, often distant from the tertiary centres. The CNS recognises and diagnoses conditions for which medication is required. Historically the CNS contacted appropriate medical practitioners to advise and arrange appropriate prescriptions. This delayed treatment, and wasted professionals' time. Government initiatives (DH 2006) to

extend the role of the Nurse to include NMP have been widely implemented (DH 2011).

Aim: To describe how this new clinical service was developed.

Materials and method: An audit by the CNS team over a 3 month period demonstrated the need for prescribing. 61 instances of prescription generation were recorded, confirming that remote prescribing was significant. The Cleft Network and employing Trust agreed funding for training and this additional service.

Key results: Three CNS's have completed training. The "P-Formulary" was developed using the data collected in the previous audit, and the supply of FP10 prescription pads is being arranged.

Conclusion: The audit trail is being developed and patient satisfaction will be monitored.

References

DH (2006), Improving Patients' Access to Medicines: A Guide to Implementing Nurse and Pharmacist Independent Prescribing within the NHS in England. Department of Health, Gateway reference: 6429
DH (2011) Evaluation of nurse and pharmacist independent prescribing Executive Summary, Department of Health, Gateway reference 15729

A retrospective two year audit of antenatal and immediate post natal care in cleft lip and palate

Karine Anne Latter

Aim: To audit against national standards and to provide data to improve service delivery

Method: A postal questionnaire divided into three sections to measured against national standards and provide feedback of quality of care. These were: About their scan experience, about their contact with the clinical nurse specialist and after their baby was born. A box to provide free text on how the service could be improved was added at the end

Results: Thirty eight of the sixty four (59 %) questionnaires were returned. Results showed a high percentage of the nursing standards were being met and provided data on patient assessment of the care provided in respect of antenatal and immediate postnatal care. Twenty-five of the thirty-eight questionnaires (65.8%) included comments on how to improve the service. Ten of these responses (40%) related to the quality of care provided by midwives in the maternity units.

Conclusion: Feedback indicated a high satisfaction with the information from scanning departments and contact with the clinical nurse specialists. Also highlighted was a lack of knowledge in maternity units concerning care from midwives especially around feeding which is mirrored in the literature.

Comparing the lip symmetry of children with repaired cleft lip with non-cleft children using SymNose: a benchmarking exercise

John Victor Williams, Richard Michael McKearney, Nigel S Mercer

Aim: To compare the differences in lip symmetry between children with repaired cleft lip and non-cleft children using the SymNose program to set a benchmark standard.

Method: SymNose was used to assess lip symmetry in 22 10-year-old children who had previously undergone primary cleft lip and palate surgery by the same surgeon (NSM). The images used for assessment were taken before alveolar bone grafting. The lip symmetry of an age-matched group of children without cleft lip was similarly assessed.

Results: Significant differences in lip symmetry between both groups were identified from the numerical data. Non-cleft lips demonstrate a natural degree of asymmetry. Although SymNose assesses lip symmetry across 5 parameters, differences between the two groups were only significant in 3 of these.

Conclusion: SymNose may be used to objectively assess post-operative lip symmetry for quality control purposes. Significant differences in lip symmetry between both groups were only seen in 3 of the 5 parameters. The study reveals that non-cleft children have naturally asymmetrical lips and the data from this comparison group may be used as a gold standard for future audit purposes.

An audit of occlusal outcomes in cases treated by the cleft lip & palate service South West over 6 years

David Heads, Scott Deacon

Design: A retrospective audit of occlusal outcomes from 2006-2011.

Setting: Cleft lip & palate service South West, North Bristol NHS Trust.

Gold Standard: Mean PAR score reduction of 69%.

Materials and Methods: Data was collected for all cases treated by the cleft lip & palate unit South West that were debonded during calendar years 2006 - 2011, inclusive. All cleft types were included and the same Consultant Orthodontist carried out the orthodontic treatment. All types of orthodontic case were included, e.g. orthognathic cases and upper arch only treatments.

Results: A total of 70 cases were completed between 2006 and 2011. Complete records were available for 86% of these cases. The mean PAR score reduction for all cases with records was 69.4%. When excluding cases that were debonded early, the mean PAR score reduction was 73.1%. The results meet the gold standard quoted in the literature.

Conclusions: This audit shows that patients at the cleft lip & palate service South West receive high quality orthodontic treatment. The results meet the standard, which was developed as a national benchmark for occlusal outcomes in unilateral cleft lip and palate cases. Occlusal outcomes should be assessed in cleft centres to assess the quality of cleft orthodontics across the UK.

Speech and Language Therapy intervention in community services across the Northern region for children with cleft palate

Philippa Humes, Stephanie Delvin

Introduction: Information regarding therapy offered to cleft patients in community services is routinely collected when patients are 5 years old. An audit of the effectiveness of the data collection before and after the introduction of an electronic form was carried out and an analysis of therapy offered in the community.

Subjects: 154 children (all cleft types) born between 2002 and 2006; 71 excluded due to incomplete data.

Method: Data from forms were collated and analysed for type of therapy offered and effects of cleft type. Response rate was investigated particularly with regard to format of the form i.e. paper or electronic.

Results: The electronic form has improved the return rate from 40% to 68%. Most children had therapy for language before the age of 5, but 15/34 children had cleft therapy in the community. The number of children who have been offered therapy for cleft type speech has remained consistent over time, although an increase in the raw data for UCLP was seen.

Conclusion: Return rate for this data has been low. However, the introduction of the electronic form has been a success allowing improved analysis regarding therapy provision for cleft patients in the community in the future.

Study to measure the clinical effectiveness of a Dental Hygienist in a Cleft Lip and Palate Unit.

Rhiannon Jones, Rosemarie Winter, Scott Deacon

Objective: To assess the clinical effectiveness of a dental hygienist within a Cleft Lip and Palate Unit by measuring oral hygiene at each visit.

Design: A prospective cohort study with data collected at each visit and plaque recorded using a modified Turesky index. Specific oral hygiene instruction given at each appointment.

Setting: The dental clinic at the South West Cleft Unit, Frenchay Hospital, Bristol.

Patients: All consenting patients with a Cleft Lip and/or Palate attending Cleft Unit between September 2010 and September 2011 that were referred to the dental hygienist.

Results: 28 patients had a second appointment to allow for comparison. Of these, 23 had a reduction in score, 2 remained the same and 3 increased.

Conclusions: Different types of periodontal diseases are prevalent in the cleft population. Oral hygiene improved significantly in most cases after referral to a hygienist.

Outcomes following adult revisional unilateral cleft lip repair
David Sainsbury, Sophie Butterworth, William Hodgkinson, Peter Hodgkinson

Introduction: Using a panel assessment and SymNose (to provide quantitative measurement of symmetry) we present our outcomes following revisional surgery for adult unilateral cleft lip.

Methods: Thirty-eight consecutive patients (19 females, 19 males) with a mean age of 23.9 years (range 16.7-51.5) underwent revisional surgery for unilateral cleft lip between 1998-2010. Twenty-three patients with pre-operative and post-operative digitised photographs were assessed by a layperson, junior and senior medical staff, using the Asher-McDade index, a global score and SymNose.

Results: All assessors' scores (lip, nose, scar, global) remained the same or improved. Scores showing significant improvement were observed for the lip ($p=0.005$) and nose ($p=0.008$) following layperson assessment and overall ($p=0.0004$) and lip scores ($p=0.01$) as assessed by senior medical staff. No significant difference in pre-operative and post-operative scores for all parameters using SymNose was seen. When assessing pre-operative photographs, SymNose and junior medical staff scores and SymNose and senior medical staff scores demonstrated correlation ($p=0.03$). The post-operative scores showed correlation between SymNose and senior medical assessment ($p=0.005$).

Conclusions: Adult cleft lip revision appears to facilitate improvement in a number of parameters when evaluated by panel assessment. Some correlation in panel and SymNose scores was observed in pre-operative and post-operative assessments.

Just an excuse for a cuddle? A review of The Spires SLT Early Advice Package
Sandra Treslove, Helen Piggott

Aim: To review the delivery of the Speech & Language Therapy Service Early Advice Care Package across twin sites (Oxford and Salisbury) including parental feedback.

What is 'Early Advice'? We offer 2 contacts with families to advise about early speech and language development, the impact of a cleft palate on speech and hearing and activities to encourage speech sound development.

Design: Internal audit and clinical review by SLTs. Questionnaire sent to parents of 72 children

Results: This will include SLT compliance with service standards (timing, duration and content of delivery) as well as qualitative parental responses to the questionnaire. The review of the Early Advice Package will consider factors such as the format of each session and consistency of delivery between SLTs.

The implications for future service delivery will be discussed. This will include any service modifications arising from parental feedback as well as service innovations proposed by SLTs during the review, such as developing a supplementary 'Early Advice DVD' and giving each family a picture book funded by CLAPA (Wessex) with which to demonstrate sound play ideas.

The development of a dedicated multidisciplinary alveolar bone graft clinic to prepare children and their families for surgery and allow national audit record collection

Jeanette Mooney, Dianne Phare, Patricia Bannister

Aim: To improve the quality of care provided to the child and family.

Design: Historically alveolar bone grafts (ABG)'s were undertaken on several sites in Greater Manchester Following surgery parents were telephoned to assess recovery and satisfaction with the received care .A lack of information and preparation for ABG both for themselves and their child was reported. A retrospective examination of the notes demonstrated significant numbers had incomplete national ABG audit records. The Cleft team acknowledged the need for a dedicated clinic to improve care and data collection. Appropriate team members were identified and a pathway developed.

Results: ABG multidisciplinary clinics have been introduced. All children are consented for surgery. They receive intensive oral hygiene instruction, preparation for surgery and a ward visit. Involvement of play therapy/ psychology is arranged if required; A postoperative information leaflet has been developed together with a data collection tool for ABG audit records

Conclusion: Both patient and audit record needs have been addressed. A future audit will be conducted to assess patient and parent satisfaction together with collection of national audit data.

Is there a dental treatment need for three year old children with a cleft lip and/or palate?

Jeanette Mooney, Helen Worthington

Aim: To report the presence of dental caries in three year old children with cleft lip and/or palate (CLP) under the care of a Regional Cleft Unit in the United Kingdom.

Design: Children in a randomised controlled trial examining a dental health programme were examined aged 3 years. This study was not powered to detect differences in caries between the study groups however the opportunity arose to report the dental health of the total group of children with CLP.

Results: 82 children, median age 44 months were examined. 60 (73%) were caries free, 5 (6 %) demonstrated enamel caries and 17 (21%) dentinal caries. The overall, mean caries experience, decayed, missing and filled teeth (dmft) was 0.51(SD 1.45) and for those 17 (21%) with dentinal caries, 2.47 (SD 2.35). Four required extractions under general anaesthesia. The majority, 75 (91 %) reported local dental care yet none had been offered dental treatment or referred for a paediatric dentistry consultation.

Conclusion: This evidence suggests a need for the Regional Cleft Unit to provide early dental care. Further research is required to improve the oral health of children with CLP.

Cleft Lip and Palate Care in Assam, India.

Helen Moreland

A reflective account following my experience as a student volunteer with Operation Smile in India between 26th March - 24th April. The poster will be mainly photo based due to the little time available between arriving home and attending the conference, however I will be open to questions during the conference.

5 year olds' index outcomes for patients with unilateral cleft lip and palate (UCLP) born 2000-2005

Joyce I Russell, Nikki E Atack

Introduction/Background: The 1998 Clinical Standards Advisory Group (CSAG) report demonstrated poorer maxillary growth for 5-year-olds with UCLP born 1989-91 than in Scandinavian centres. This study aimed to audit UCLP maxillary growth of children born during the subsequent reorganisation.

Material and Methods: Since 2007, at the annual CFSGBI Orthodontic Special Interest Group meetings, study models for 5-year-olds with UCLP have been independently assessed using the 5 Year Olds’ Index (Atack et al 1997).

Results: There has been a gradual increase in the number of records, although this includes dental photographic records. In 2012, for the first time, all UK centres participated, submitting records from those born in 2005. For 2000 – 2005 the records of 699 patients with UCLP, from 1001 known, were assessed (70% inclusion rate). The outcomes were 45% excellent/good (groups 1/2); 31% fair (group 3); 25% poor/very poor (groups 4/5). The outcomes for those born in 2005 were: 42% excellent/good; 43% fair; 16% poor/very poor.

Conclusion: There is annual variation in outcomes. However, for patients born 2000 - 20005 there is improved maxillary growth compared with the CSAG outcomes for those born 1989-1991.

A novel patient controlled bi-directional palatal lift appliance
Louise Eleanor Greene, Kevin Wilson, Grant McIntyre, Jan Wilson, Felicity Mehendale

Palatal lift appliances have a role in the management of velopharyngeal dysfunction for relatively immobile palates of adequate length where surgery is contra-indicated. For a palatal lift to be effective it needs to lift the posterior part of the soft palate. Achieving this with a traditional appliance involves acrylic or wirework adjustment over successive appointments until the patient is able to tolerate without gagging.

A novel palatal lift appliance has been developed incorporating a screw section to incrementally distalise the lifting plate in addition to a flexible spring arm for vertical adjustment. Patients are taught how to increase plate extension incrementally on a daily basis. This increases compliance and is easier to tolerate than traditional step-wise adjustment. The number of clinic appointments and burden of care is reduced allowing multidisciplinary clinics to be better utilised for appliance fine tuning to optimise velopharyngeal function. Videofluoroscopy and/or nasendocospy are used to visualise the soft palate with the appliance in place, with the screw and flexible arm adjusted to ensure satisfactory positioning.

The design and construction of the appliance is described with supporting clinical images. The new appliance reduces the number and length of clinic appointments and is more comfortable for the patient.

Peri-operative analgesia regimes used for Cleft Lip and Palate surgery in the UK and Ireland.
Russell Perkins, Hilary Ann Eason

Cleft Lip and Palate (CLP) surgery is painful requiring long acting analgesia with minimal respiratory depression. We use an analgesia protocol comprising intra-operative paracetamol , remifentanil , dexamethasone and post-operative regular paracetamol with “as required” ibuprofen and morphine.
We are considering introducing a “non-standard” analgesic (clonidine) and so wondered what regimes are followed elsewhere

Anaesthetists in 19 CLP centres in the UK and Ireland were surveyed over 6 months in late 2011.

The response rate was 79% - 73% were from Paediatric Hospitals. The respondents estimated 60 to 400 CLP surgeries were performed in their centres annually – (median=135) with 48 “regular” anaesthetists. 40% have a formal protocol for CLP perioperative analgesia.
Pre-medication is only used in one centre.
All give intra-operative and regular post-operative paracetamol.
All use a non-steroidal post-operatively -33% prescribe this “as required.” Opiates are largely also “as required” prescriptions with two centres using infusions. Only one centre uses remifentanil. Very few centres use “non-standard” analgesics.

Our practice is currently similar to most except our use of remifentanil. In light of these findings we will re-audit our regime to ensure we are achieving acceptable pain scores with minimal side effects before considering the addition of a “non-standard” analgesic.

Romberg Parry Syndrome: A Photographic History of Progression and Outcomes in 3 consecutive cases in a single unit.
Kanwalraj Moar, Sophie Butterworth, Peter Hodgkinson

Romberg Parry Syndrome is a rare syndrome also known as hemifacial atrophy. It is characterised by slowly progressive localised atrophy of the skin and underlying connective tissue (including fat, fascia, cartilage and bones) on one side of the face. Although poorly understood there is known progression sometimes beginning as a linear defect but extending up to complete hemifacial deficiency. It may start in the first decade of life and progress through the teenage years. Disease progression eventually ceases leaving a severe residual facial deformity.

The aim of this series of 3 patients is to give a visual photographic history of the disease progression and treatment outcomes helping the inexperienced clinician to recognise the condition. The patients were diagnosed early and treated within a Multidisciplinary team environment including Plastic Surgery, Orthodontics and Psychology. Regular photographic clinical records demonstrate the devastating impact of the disease and subsequent treatment with a combination of fat transfer, free tissue transfer and secondary cosmetic/ resuspension surgery.

Case 1: female diagnosed at age 9 with a left hemifacial atrophy.
Case 2: male diagnosed at age 8 with a left hemifacial atrophy.
Case 3: male diagnosed at age 12 with a right hemifacial atrophy.

Jakes Catheter: A technique to reduce soft tissue trauma in Le Fort 1 osteotomies
Kanwalraj Moar, Emma Woolley

This technique provides a neat, simple and effective method of reducing soft tissue trauma during Le Fort I osteotomy.

Once Le Fort I osteotomy cuts have been completed and the maxilla down fractured many surgeons will place a bur hole through the anterior nasal spine through which to pass a wire. The twisted wire controls and mobilises the down-fractured maxilla but can easily cause trauma to the soft tissues as it is placed under tension.

A Jakes Catheter is a red urinary catheter of 10, 12 or 14 french size, made of latex and costs approximately £0.52. A length of Jakes catheter is placed over the twisted wire providing a neat durable cover. A Lawson Tate clip is applied to the free end of the wire: covering the sharp ends of the wire, providing control and prevents the catheter from slipping free (Figure 1: Photograph). The red colouration of the catheter highlights its position without obscuring the surgical field or reducing mobility. In addition by bending in the ends of the wire over the catheter, the wire can be left in situ for a period of time post operatively, e.g. wire intermaxillary fixation without causing significant extra trauma.

School Change Day: A workshop-based intervention incorporating a photography project for children with a cleft lip and/or palate facing the transition to secondary school

Catherine Keen, Joanna Blundell, Zoe Edwards, Kathryn Da-Costa-Greaves, Jayne O'Connell

Children with a cleft lip and/or palate may encounter several social challenges within the school environment, and times of transition can be particularly challenging. Research highlights the usefulness of group interventions in improving a child's ability to manage social situations and increasing resilience and confidence (Kish & Lansdown, 2000; Maddern & Owen, 2004). In June 2011 the North West England, Isle of Man and North Wales Cleft Lip and Palate Network ran a workshop event for children under their care due to move to secondary school. Nine children and 13 parents attended the event, which comprised parallel child and parent sessions. Subjects including communication, problem solving and managing difficult situations were covered. The children also participated in an Arts for Health photography project which aimed to promote confidence. Evaluation following the workshop revealed that the majority of parents and children had found the event beneficial, demonstrated by a reduction in the overall number of concerns reported. Qualitative feedback highlighted the benefits of a group event and the value of being able to share concerns with others. A reunion event was held in October 2011 during which families reported the positive impact of the workshop on the children's subsequent school transition.

Midfacial augmentation in teenage cleft patients using malar and paranasal Medpore implants

Duncan Atherton, Piet Haers

Introduction: Malar and paranasal implants offer a way to augment and reconstruct malar hypoplasia and mid facial defects. These implants can be used as temporising procedures in young teenagers whom, with the support of the unit psychologists, are felt to have sufficient social and psychological reasons to warrant their use.

Methods: Two patients are presented aged 14 and 15 who underwent such a procedure. Access was achieved via a labial mucosal approach and "super petite" and "petite" malar and paranasal Medpore implants were inserted in a subperiosteal plane and secured with titanium screws.

Results: Both patients underwent an uneventful postoperative recovery and at a follow up of three and ten months, both remain pleased with their reconstruction.

Discussion: An early recontouring of the face allows improvement of facial hypoplasia in patients with particular emotional or psychological concerns. These patients need to be carefully selected with the support of the unit psychologists. This procedure allows growth and alveolar development to continue until definitive orthognathic surgery can be carried out and is a valid alternative in cases where early distraction is not felt to be appropriate.

Gorlin-Goltz Syndrome associated to cleft lip and palate: report of 3 patients

Susana Dominguez-Gonzalez, Madhavi Kondapuram Seshu, Joyce Russell

Objectives: Gorlin-Goltz Syndrome (GGS), also known as Naevoid Basal Cell Carcinoma Syndrome or Basal Cell Naevus Syndrome, is characterised by the presence of four primary symptoms (multiple nevoid basal cell epitheliomas, jaw keratocysts, skeletal anomalies and intracranial calcifications). Jaw Keratocysts (JK) may be the first indication of the presence of GGS. JK are present in about 80% of individuals with this syndrome and it has a strong recurrence rate. It has been described an increase in the number of orofacial cleft seen in GGS patients. The objective of this study is to describe the characteristics of GGS and its association with cleft lip and/or palate based on the findings in our patients.

Materials and Methods: Three patients born with cleft lip and/or palate (1 incomplete cleft lip, 1 complete unilateral cleft lip and palate and 1 incomplete bilateral cleft lip and alveolus) and treated at Alder Hey Hospital who developed multiple recurrent cysts of the jaw were identified.

Results: Histopathology reports diagnosed the cysts to be Keratocysts. Referral to geneticists helped to confirm the diagnosis of GGS in these patients with mutations of PTCH gene. They also presented with other features of the syndrome including skin lesions, rib abnormalities and macrocephaly.

Conclusion and clinical application of study: The presence of recurrent jaw cysts could be the first symptom of a cleft patient affected by GGS. Enucleation of the cysts and histopathology diagnosis, follow by a referral to the geneticist is vital. Other relevant specialities should also be included for a comprehensive multidisciplinary treatment.

References
Lambrecht JT, Kreusch T. Examine your orofacial patients for Gorlin-Goltz Syndrome. Cleft Palate-Craniofac J 1997; 34 (4): 342-50.

"I am fed up with being so different from everyone else, my face, my speech and hearing aids…" Reflections and recommendations from BCLP clinical records

Anne Harding-Bell, Victoria Parfect, Rachel Fulluck, Amandine Woodham

This expression of frustration from a 6 year old boy with a Bilateral Cleft Lip and Palate prompted a review of service needs for Children born with BCLP. 5 yr audit records for 17 cases of BCLP born 2000-2004 were reviewed for the burden of care in3 disciplines – surgery, speech and hearing.

Results:
Surgery: 17 children treated by 3 surgeons had undergone 2 – 8 surgical procedures each; 11/17 cases underwent more procedures than originally planned and 12/17 underwent fistula repair.
Hearing: 14/17 had required ongoing hearing management
Speech: 8/17 still required speech and language therapy for structural or hearing related issues an unfavourable result in relation to national standards

Conclusions: Severity of cleft ,numbers of surgical procedure and middle ear history co-occur in this group and speech problems are more severe tending not to resolve by age 5yrs. The emotional consequences of speech and hearing problems will be compounded by the strain of undergoing multiple surgical procedures It is proposed that children born with bilateral cleft lip and palate should be prioiritsed for early SLT intervention and specialist psychological support.

Development of recruitment strategies for the TOPS trial (Timing of Primary Surgery for Cleft Palate)

Trisha Bannister, Jeanette Mooney, Nicola Harman (on behalf of the TOPS study group)

Objective: Recruitment rates in the TOPS trial vary across centres and overall the recruitment rate is lower than expected. The objective of this study is to identify key challenges associated with recruitment to TOPS and to develop a set of recruitment guidelines aimed at improving recruitment rate.

Methods: 14 months after trial opening clinicians involved in recruitment to TOPS from 9 UK centres were invited to participate in a half day workshop. Centres were represented by specialist and research nurses, speech therapists and cleft unit coordinators. Groups were asked to identify the challenges associated with recruitment to TOPS. Challenges were reviewed and grouped according to key themes and groups asked to discuss and feedback solutions.

Results: Key challenge themes that emerged were: Clinician equipoise; delivery of trial information and gaining rapport; parental preference for randomisation arm; burden of care and organisational challenges. Participants developed solutions to these challenges which formed the document “Top tips for TOPS recruitment”.

Conclusion: Recruitment challenges specific to the patient group are important considerations in clinical trials. In TOPS researchers have contributed to the development of TOPS specific recruitment guidelines which will be circulated to all centres and their impact on recruitment rate assessed