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## Abstract Book



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# Free Paper Session 1 - Speech & Intervention

## Results from a pilot randomised control trial (RCT) of ultrasound visual biofeedback versus standard intervention

**Dr Maria Dokovova**<sup>1</sup>, Dr Joanne Cleland<sup>1</sup>, Lisa Crampin<sup>2</sup>, Lindsay Campbell<sup>2</sup>

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**Introduction:** Ultrasound visual biofeedback (U-VBF) is a useful tool for speech intervention with children with CP+/-L because it displays real time tongue movements. Despite a growing evidence base of its application in speech therapy, the evidence for using it with children with CP+/-L specifically is minimal.

**Aims:** This pilot assessed the feasibility of a large-scale RCT comparing intervention with ultrasound visual biofeedback to standard treatment for children with CP+/-L. It aimed to determine recruitment, attrition, and outcome measure completion rates (target: 75% completion per measure). The acceptability of randomisation and the treatments to the children and their families are reported separately.

**Methods:** 19 children aged 4;6-16 were randomised to either 6 sessions of ultrasound intervention or articulatory intervention, stratified by age. Percentage of target correct consonants (PCC) were measured by assessors, blind to treatment groups. PCC was based on audio recordings of treated and untreated probes, taken before and during treatment, and a week and a month after treatment. Patient-reported outcome measures on Intelligibility in Context Scale (ICS) (McLeod et al. 2012) and quality of life with CLEFT-Q (Klassen et al. 2018) were completed before and after treatment.

**Results:** Recruitment: 32 families approached, 19 consented (59% conversion rate), ~50% of target.

Attrition: 11%

- Outcome measures completion:
- Audio for PCC: 92%
- ICS: 95%
- CLEFT Q: 93%
- Therapy dose reports: 96% and only one session did not reach the minimum target of 100 trials per session (mean=223, SD=68, Single Score Intraclass Correlation agreement=0.81)

**Conclusions:** Despite a low recruitment rate, there was low attrition and all other targets were met. Reasons for low recruitment are explored in separate qualitative studies. A larger scale RCT is feasible, subject to defining a recruitment target in a power analysis and an improved recruitment protocol.



## Acceptability of Ultrasound Visual Biofeedback and Articulation Intervention to Parents and Children.

**Dr Joanne Cleland**<sup>1</sup>, Robyn McCluskey<sup>1</sup>, Dr Marie Dokovova<sup>1</sup>, Lisa Crampin<sup>2</sup>, Lindsay Campbell<sup>2</sup>

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**Background:** Ultrasound visual biofeedback (U-VBF) has the potential to be useful for the treatment of compensatory errors in speakers with CP+/-L, but there is little research on its effectiveness nor on how acceptable families find the technique. This study reports on parents' and children's perspectives on taking part in a pilot randomized control trial comparing U-VBF and articulation intervention. Quantitative results will be reported separately.

**Aims & Objectives:** To determine the acceptability to families of children with CP+/-L of:

- Randomisation in a clinical trial
- UVBF
- Articulation intervention

**Methods:** Participants were 19 children aged 5 to 13 with CP+/-L and their families. Children were randomised in a 1:1 ratio, stratified for age. Mixed methods were employed: Two questionnaires to determine the acceptability of U-VBF and articulation intervention respectively; and semi-structured focus groups/interviews. Responses to questionnaires were analysed for frequency of positive versus negative acceptability. The focus groups/interviews were analysed using thematic analysis and coded using the theoretical framework of acceptability.

Results & Conclusions: All participants responded to the questionnaires. More than 75% of families rated randomisation as acceptable and more than 75% of families rated both interventions as acceptable, with the caveat that half of participants did not wish to continue articulation intervention after the study.

Six families (3 in each intervention) volunteered to take part in the focus groups/interviews. Results show more positive than negative themes regarding acceptability, particularly affective attitude where high levels of enjoyment were expressed, although some participants found the articulation intervention “boring”. In both groups there was a considerable burden involved in travelling to the hospital location.

In conclusion randomisation is acceptable to families; U-VBF is enjoyable; and the burden of the additional outcome measures required for a clinical trial are manageable although there is a travel burden for participants.



## **Evaluation of Speech Outcomes following Palate Re-Repair: Application of the CAPSA and VPC-Sum**

**Dr Samantha Calladine**<sup>1</sup>, Effie Jarvis<sup>1</sup>

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Background: Around 30% of children born with cleft palate +/- lip in the UK develop speech difficulties caused by structural anomalies, including velopharyngeal insufficiency (VPI). Palate re-repair is one of the surgical interventions used to treat VPI in the UK and has been used at the Leeds cleft unit since its inception. Patients' post-operative follow-up includes a detailed speech assessment, although speech outcomes have not been systematically evaluated. This study addresses this using nationally recommended methods for speech evaluation.

### **Aims**

1. To evaluate speech outcomes in individuals born with cleft palate +/- lip following palate re-repair by a single surgeon
2. To pilot a systematic procedure for speech analysis and outcome evaluation

Methods: A retrospective analysis was undertaken of pre- and post-operative speech recordings for patients who underwent palate re-repair between 2003 and 2019. 44 patients (age range 3;7-40;5) were included. Recordings were analysed using the CAPSA by two external specialist speech and language therapists blinded to the nature and aims of the study. Inter and intra-rater reliability measures were obtained. Pre- and post-operative VPC-Sum scores were derived from CAPSA ratings based on the system described by Pereira et al. (2021). Changes in CAPSA ratings were analysed statistically.

Results and Conclusions: The analysis found significant improvements in hypernasality ( $p < 0.001$ ) and passive cleft speech characteristics ( $p < 0.001$ ). 25/44 (56.8%) patients achieved absent or borderline hypernasality post-operatively. VPC-Sum scores for the group decreased from 1.93 pre-operatively to 1.05 post-operatively.

The findings add to the evidence base for palate re-repair as an intervention for cleft palate-associated VPI. This will enhance the quality of clinical discussion regarding intervention and allow better informed patient/parent consent. The experience obtained during this study will inform the development of a more methodical approach to the evaluation of speech intervention at the Leeds unit and may inform practice elsewhere.



## **Auditory processing of children with cleft lip and palate: a study using standardised parent report**

**Dr Stephanie van Eeden**<sup>1</sup>, Amy Davies<sup>2</sup>

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Background: There is evidence to suggest that some children with cleft lip and/or palate (CL±P) have poor auditory processing (AP). This may impact speech development as well as language and reading skills.

### **Aims**

- To evaluate the AP skills of children with non-syndromic CL±P according to cleft type
- To investigate associations with hearing loss, speech intelligibility, language, and the auditory environment.

Methods: Participants were recruited through the Cleft Collective study (n=146). Parents of children 5-8yo (all non-syndromic cleft types) completed the Evaluation of Children's Listening and Processing Skills (ECLiPS) parental questionnaire online using REDCap technology. Data were analysed along with data from the questionnaires in

the main study regarding speech intelligibility and language. Data from the Language ENvironment Analysis (LENA) recordings made at 13-months were available for 38 participants, which allowed for analysis of the impact of background noise in the home.

Results: The mean score for AP measures for children with CL±P was 2 scaled scores lower than the normative average score of 10. Parents of children with a cleft involving the palate reported lower scores than those with cleft lip only. Those with a history of hearing loss were 3X more likely to have poor AP skills than those without (OR:3.19 [95% CI:1.31-7.77], p=.011). AP skills were correlated with intelligibility (r =.502, p <.001) and language (r =.395, p <.001) at 5-years. In children under 2-years, parental concern about hearing also predicted later AP skills; high levels of background noise in the home did not.

Conclusions: Children with CL±P are at risk of poor auditory processing. A history of hearing loss was most strongly linked with later listening skills which themselves were linked with poorer intelligibility and language skills. We should be more vigilant with early hearing difficulties and aware of their long-term consequences.



## **Evaluation of speech outcomes for children born with Pierre Robin Sequence**

**Sharon Baker**, Michaela Rowe, Helen Extence, David Drake, Thomas Jovic

Background: Children born with Pierre Robin Sequence (PRS) are reported to have an increased risk of difficulties with palatal function and speech production in comparison to their peers born with a cleft palate only (CPO) (Shwaiger et al., 2021; Gustaffson et al., 2019; Hardwicke et al., 2016).

Aims and Objectives: To review speech outcomes for those born with PRS at the Welsh Centre for Cleft Lip & Palate in order to provide tailored advice and guidance to parents/carers and to determine whether any changes to the care pathway were required.

Methods: A retrospective casenote review was conducted of children born with CPO between 2014-2018 who had palatal surgery at The Welsh Centre for Cleft Lip & Palate by a single surgeon. Data related to method of feeding, airway management, velopharyngeal function and speech outcomes at age three and five were collated. Outcomes for children born with PRS were compared with those born with CPO.

Results: There were 53 children included (19/53 had PRS and 34/53 had CPO). Mean age of palate repair was seven months for the PRS group and six months for the CPO group. Secondary surgery for speech was required for 13 children before age five years, 5/19, 26% of the PRS group and 8/34, 24% of the CPO group. Cleft speech characteristics (CSCs) were present at age three for 20 children, 7/19, 37% of the PRS group and 13/34, 38% of the CPO group.

Conclusion: Children born with PRS who had palatal surgery at The Welsh Centre for Cleft Lip and Palate have speech outcomes comparable to children born with CPO. At present, the speech pathway for children born with PRS does not need to include any additional support beyond routine monitoring. Outcomes will continue to be monitored to ensure the level of risk does not change.



## **Exploratory study into the relationship between timing of surgery, babble development and speech and language**

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Background: The Timing of Primary Surgery (TOPS) trial was an immense undertaking. Many UK cleft centres were involved. The main findings were reported in 2023 with the focus on velopharyngeal function at 5-years. Variables of interest that were collected and not reported include articulation development and its relationship to expressive language at 5-years.

Aim: To investigate the relationship between the timing of primary surgery, consonant development, and expressive vocabulary.

Methods: Design: Retrospective exploratory study.

Setting: Newcastle cleft centre.

Participants: Patients who were part of the TOPS trial; non-syndromic cleft palate only with speech and language records at 18m, 3y and 5y (n=34).

Data collection: Timing of surgery (6m vs 12m); canonical babbling at 12-months; consonant inventories at 18-months and 3-years; velopharyngeal function at 5-years; articulation at 5-years; vocabulary at 5-years.

Data analysis: Descriptive statistics will explore differences between surgery at 6-months and 12-months. Logistic regression will examine associations between consonant inventories and expressive vocabulary at 5-years.

Results: Participants in the 6-month group had poorer velopharyngeal function at 5-years, but better articulation than the 12-month group. The 6-month group had larger consonant inventories at 18m, but no differences were seen at 3-years. There was a relationship between early consonant inventories and later vocab measures, with the development of fewer than four consonants at 18m predicting 19% of variance in expressive vocabulary measures at 5-years. This was not as a result of the timing of surgery or hearing status and there was no correlation with cleft width.

Conclusions: This was an exploratory study which found some evidence for associations between consonant development and expressive vocabulary. These were not related to the timing of surgery. Large-scale replication of this study is warranted to increase our understanding of outcomes from the TOPS study and the importance of early consonant development to later outcomes.



## **5-year Speech Outcomes and Secondary Speech Surgery Rate in Wide Isolated Cleft Palate**

**Hannah Latham**<sup>1</sup>, Prof Jenny Thomson<sup>2</sup>, Anne Roberts<sup>1</sup>, Alistair Cobb<sup>1</sup>

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Background: Cleft palate width has been identified as a predictor of velopharyngeal insufficiency (VPI). There remains little research around the impact of cleft palate width on the emergence of cleft speech characteristics (CSCs).

Aims: The study explores whether children born with a wide isolated cleft palate are at greater risk of persistent CSCs and need for secondary speech surgery. Associated variables are considered; including timing of primary palate repair and Robin Sequence.

Methods: Primary cleft palate repairs by a single surgeon from birth cohorts 2000-2012 were identified through the Cleft Registry and Audit Network. Cases were assigned to a Wide or Non-wide group by the surgeon based on clinical definition: "a cleft palate is considered to be 'wide' when the combined width of the two palatal shelves appears to be equal to or less than the width of the cleft".

Analysis of previously collected CAPS-A (Cleft Audit Protocol for Speech-Augmented) data compared 5-year speech outcomes between the two groups. Rates of secondary speech surgery were explored beyond age 5.

Results: There were significantly greater ( $p = .001$ ) Red CAPS-A speech outcomes, indicating a significant articulation difficulty in the Wide group; backing to velar/uvular, pharyngeal/glottal articulation and active nasal fricatives the most commonly occurring CSCs. Secondary surgery for VPI was significantly greater ( $p = .006$ ) in the Wide group. Surgery for palatal fistula was also greater but not significant ( $p = .285$ ).

Conclusions: Findings support the hypothesis that children born with a wide isolated cleft palate are likely to require on-going speech therapy at school-start age for significant articulation difficulties, and increased likelihood of secondary speech surgery. Further research into speech outcomes and cleft palate width in all cleft types is needed, along with the influence of associated variables, e.g. hearing, timing of primary palate repair and Robin Sequence.



## Speech pathway digital resource to support cleft speech practice at home/school

**Claudine Milligan**<sup>1</sup>, Wendy Blumenow<sup>1</sup>, Conor Peacock<sup>1</sup>, Laurence Glennon<sup>1</sup>, Alex Bowman<sup>1</sup>

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Introduction: Approximately 70% of children with a cleft palate (+/- lip) require speech therapy (Hardin Jones et al, 2005). A recent study by McFaul et al (2022) highlights the number of practices is vital to speech progress. Speech and Language Therapists (SLTs) rely on families and teaching staff to practice in between therapy sessions. Families often report children lack motivation to practice. Currently at our cleft centre we do not have a specific method to prescribe and monitor at home speech practice. SLTs use a range of different paper-based activities and written instructions.

Purpose: This project proposes to design an individualised digital prescription for cleft speech therapy. This will aim to improve children's speech practice at home/school, in order to achieve quicker speech gains, and reduce the number of therapy sessions required.

This resource does not aim to replace SLT guidance or parental/carer support during speech practice.

Methods/results: Our desired solution aims to provide children with immediate feedback, motivation to practice through gamification, guidance for sound production with videos and progress monitoring by the SLTs. We secured charitable funds to proceed. A suitable developer was identified, and the team is now focusing on designing a Minimum Valuable Product.

Conclusion: Once a suitable MVP is designed the plan is to implement a pilot study to evaluate its effectiveness. After the MVP build phase, we plan to launch the full platform build phase. Beyond this phase the aim will be to complete a randomised clinical study to evaluate the effectiveness of this resource more robustly.

References: Hardin-Jones MA, Jones DL. Speech production of preschoolers with cleft palate. *Cleft Palate Craniofac J.* 2005 Jan;42(1):7-13.

McFaul H, Mulgrew L, Smyth J, Titterton J. Applying evidence to practice by increasing intensity of intervention for children with severe speech sound disorder. *BMJ Open Qual.* 2022 May;11(2)



## Pandemic related social restrictions and early speech/language development in children born with a cleft.

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Background: Communication environment is important for early speech and language development. Social restrictions during the pandemic potentially impacted children's communication environment and experiences. It is not known if early speech and language development in children born with a cleft was impacted by these restrictions. This study aimed to examine whether the pandemic impacted early language development and consonant inventory size in children born with cleft lip and/or palate (CL/P).

Method: Utilising The Cleft Collective resource, data for children with CL/P aged 18-24 months from before the pandemic, were compared with data for children who experienced pandemic related social restrictions. Data from the Ages and Stages Questionnaire – Third Edition (ASQ-3) communication domain, completed as part of parent questionnaires at age 18 months, and Speech and Language Therapy (SLT) assessments for children with cleft palate, between ages 18-24 months were analysed using ordinal chi<sup>2</sup>, ordinal logistic regression, Fishers Exact tests and Poisson regression, and adjusted for confounders.

Results: There was no difference in ASQ-3 communication domain categorisation at 18-months between the pre-pandemic and pandemic impacted groups (n=472; ORadjusted 0.89; 95% CIs 0.433, 1.812; p=0.739). Over half (10/18, 55.6%) of the SLT assessments in the pandemic impacted group were conducted virtually in comparison to none pre-pandemic. There was no evidence for a difference between groups for SLT judgements of expressive language (n=193; p=1.00) or size of consonant inventories (n=186; IRRadjusted 0.98; 95% CIs 0.775, 1.249; p=0.896).

Conclusions: There was no evidence from these data that early language development and consonant inventory size were different in children whose first 18-24 months were impacted by the pandemic. Small sample sizes in the pandemic impacted groups and limitations of the measures used should be considered in interpretation. Early speech and language development continues to require monitoring and support in children born with cleft palate.

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## A 36-year review of speech and language in patients with Crouzon syndrome with acanthosis nigricans.

**Sarah Kilcoyne**<sup>1</sup>, Paula Scully<sup>2</sup>, Sarah Overton<sup>1</sup>, Sally Brockbank<sup>1</sup>, Gregory Thomas<sup>1</sup>, Miss Rosanna Ching<sup>1</sup>, Jayaratnam Jayamohan<sup>1</sup>, James Ramsden<sup>1</sup>, Jon Jones<sup>1</sup>, Prof Andrew Wilkie<sup>1,3</sup>, David Johnson<sup>1</sup>

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**Background:** Crouzon syndrome with acanthosis nigricans (CAN) is caused by the specific mutation c.1172C>A (p.Ala391Glu) in the fibroblast growth factor receptor 3 (FGFR3) gene, and has an estimated prevalence of 1:1,000,000 births. Most cases occur de novo, however autosomal dominant inheritance may occur. The clinical presentation typically includes craniosynostosis, midface and maxillary hypoplasia, choanal atresia/stenosis, hydrocephalus, and intracranial hypertension. Patients develop acanthosis nigricans, a hyperkeratotic skin disorder. We present the first known study to investigate the speech, language, hearing and feeding of patients with CAN.

**Methods:** A retrospective case note review of patients with a genetically-confirmed diagnosis of CAN attending the Oxford Craniofacial Unit during a 36-year period (1987-2023) was undertaken.

**Results:** Participants were six patients with genetically-confirmed CAN (5 females, 1 male), all cases arose de novo. All patients had craniosynostosis (n=5/6 multisuture synostosis, n=1/6 left unicoronal synostosis). Hydrocephalus was managed via ventriculoperitoneal shunt in 67% (n=4/6) of patients, and 67% (n=4/6) had a Chiari 1 malformation. Patients had a complex, multifactorial feeding history complicated by choanal atresia/stenosis (100%; n=6/6), and significant midface hypoplasia. All patients required airway management via tracheostomy (83%; n= 5/6); and/or continuous positive airway pressure (CPAP) (67%; n=4/6). All patients underwent adenotonsillectomy (100%; n=6/6). Initial failure to thrive, low weight and/or height were seen in 100% (n=6/6) patients; 80% (n=4/5) had reflux; 100% (n=6/6) had nasogastric (NG) or percutaneous endoscopic gastrostomy (PEG) based feeding during their treatment journey. All patients had hearing loss (100%; n=6/6). Early communication difficulties were common: receptive language disorder (50%; n=3/6); expressive language disorder (50%; n=3/6); and speech sound disorder in 50% (n=3/6) - necessitating the use of Makaton in 80% of patients (n=3/5).

**Conclusions:** Patients with CAN experience significant respiratory, neurological and structural obstacles to hearing, speech, language and feeding. We present a recommended pathway for management to support patients.

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# Free Paper Session 2 - Surgery & Tech

## Could Convolutional Neural Networks transform cleft appearance outcome assessment?

**Matt Fell**<sup>1</sup>, Dr Paul Bakaki<sup>2</sup>, Dr Ting Li Su<sup>3</sup>, Dr Aristides Tagalakis<sup>2</sup>, Professor Ella Pereira<sup>2</sup>, Prof Yonghuai Liu<sup>2</sup>, Bruce Richard<sup>4</sup>

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**Background:** There is a pressing need for an automated measure of appearance outcome following surgical reconstruction of a cleft lip. Convolutional neural networks (CNNs) represent a breakthrough in artificial intelligence image classification, and by creating multiple feature maps with filters and activation functions, can convert an input (2D image) directly into an output (appearance score).

**Aims and Objectives:** To assess the accuracy of a computational approach to cleft lip appearance outcome assessment from a 2D image.

**Methods:** Cropped facial images from the Cleft Care UK Study of 237 children with repaired unilateral cleft lip and palate at 5 years of age, were used as the training dataset. Five human raters had scored the appearance outcome from 1 (excellent) to 5 (poor). The test set consisted of 25 images with the highest inter-rater reliability of 29 humans scoring 76 images.

A CNN model was created, using transfer learning from pre-trained image datasets (VGG16, ResNet 50 and MobileNetv1) to enable anatomical feature analysis of the cropped facial images. Regression analysis estimated the relationship between the identified anatomical features and the human rater scores. The outcome is an automated score (1-5) based on mapping facial features into their corresponding class. The CNN model was tested on the 25 images novel to its learning data set.

**Results/Conclusions:** The appearance outcome score from the optimised CNN model output had high correlation with the median human rater scores (Pearson's correlation 95.5%). This outperforms previous computational methods in the literature including shape analysis (Pearson's correlation 39.6%) and the hybrid key landmarks method (Pearson's correlation 56.7%).

This study demonstrates the effectiveness of a CNN model to automatically identify anatomical features from cropped 2D facial images and create an accurate appearance outcome score estimate. Future work will focus on further model optimisation and testing on larger cleft image datasets.



## Demystifying the suprazygomatic maxillary nerve block in paediatric cleft palate surgery

**Matt Fell**<sup>1</sup>, Dr Lynn Fenner<sup>1</sup>, Nefer Fallico<sup>1</sup>

<sup>1</sup>Spires Cleft Centre, Salisbury, UK

**Background:** The suprazygomatic maxillary nerve (SZMN) block has been shown to produce effective peri-operative analgesia for the soft and hard palate. Despite this, there has not yet been widespread adoption of the technique amongst cleft surgical teams and this may be due to anatomical complexity of the pterygopalatine fossa.

**Aims and Objectives:** To assess the safety profile and efficacy of the SZMN block using the anatomical landmark technique, following introduction into the clinical pathway.

**Methods:** A retrospective cohort study was carried out in a single cleft centre in the UK. Patients born with a cleft palate (with or without a cleft lip) undergoing palatal surgery between the ages of 9 months and 18 years in June 2022 to November 2023 were included. Outcome measures were complications, intra- and post-operative opioid administration.

**Results/Conclusions:** The clinical anatomy of the SZMN block is portrayed in a stepwise approach from superficial to deep structures. 43 patients underwent surgical interventions involving the palate (either intravelar veloplasty, Furlow palatoplasty or bilateral myomucosal buccinator flaps for palatal lengthening). 22 patients in the non-block group had a general anaesthetic and local anaesthetic infiltration alone, whereas 21 patients had a SZMN block in addition to the general and local anaesthetic. There were no local or systemic complications associated with the

SZMN block. There was no difference in the total dosing of intra (p=0.93) or post-operative (p=0.79) opioids between the groups.

We demonstrate the feasibility and safety of this procedure, without the use of ultrasound guidance, in a heterogenous group of paediatric patients undergoing palatal surgery. Regional anaesthesia should be considered as part of the multi-modal analgesic strategy, although it may be difficult to demonstrate a change in opioid use in clinical settings, where enhanced recovery techniques are established and opioid use is already low.



## **Genome wide association study in UK population identifies common genetic variants for cleft palate**

Dr Sethlina Aryee, Dr Evie Stergiakouli, Amy Davies, Karen Ho, Dr Kerstin Ludwig, Dr Carlo Maj, Dr Elisabeth Mangold, Prof Deborah Lawlor, Dr Gemma Sharp, Dr Yvonne Wren, Prof Jonathan Sandy, Dr Tom Dudding, **Prof Sarah Lewis**

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**Background:** Most orofacial clefts have a complex aetiology with several genetic factors and adverse environmental exposures contributing to risk. Genome wide association studies (GWAS) have identified many common genetic variants which are associated with cleft lip with or without palate, but there have been fewer GWAS of cleft palate only and these have not been as productive. Given that cleft palate only is the most common cleft subtype in the UK it is important to improve our understanding of how these clefts arise.

**Aim:** Our aim was to use genetic information from the Cleft Collective to identify common genetic variants associated with cleft palate only in the UK population.

**Methods:** We carried out a genome wide transmission disequilibrium test (TDT) on a subset of 302 cleft palate only child-parent trios from the Cleft Collective using over 5.1 million common genetic variants imputed from data generated using the Illumina Global Screening Array v3. We also conducted a case-control analysis, using children from the Cleft Collective as cases and children from the Millenium cohort as controls.

**Results/Conclusions:** We identified two distinct genomic regions associated with cleft palate; chromosome 1 q32.3 (lead SNP rs509655 p-value =  $2.3 \times 10^{-8}$ , OR = 2.18), and 17q24.3 (lead SNP rs62070608 p-value =  $3.20 \times 10^{-8}$ , OR = 0.31). Rs509655 falls within an intronic region of the USH2A gene, mutations in which cause retinitis pigmentosa (RP) and Usher syndrome. Rs62070608 falls within a gene desert region approximately 1.4 Mb upstream of the Sox9 gene (known to cause Pierre Robin Sequence), where long range enhancers for the gene have been located. In conclusion, our analysis has identified two independent gene regions associated with cleft palate, both of which have strong biological plausibility for a role in cleft palate development.



## **Staging the BCLP Hard Palate: a Single Surgeon's Experience with Three Planned Operations**

**Theodore Pezas**<sup>1</sup>, Amy Darters<sup>1</sup>, Paul Morris<sup>1</sup>

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**Background or Introduction:** Patients with bilateral cleft lip and palate present unique challenges with regards to their surgical management. Palate repair in this cleft type is at highest risk of complication, often owed to a combination of excessive gap width and anterior displacement of the premaxilla which can result in undue tension of repaired tissues, with higher incidence of ischaemia and wound breakdown. Speech outcomes are also worse compared to those of other cleft types.

**Aims & Objectives:** To audit surgical outcomes from a single surgeon's experience of utilising the versatility of a staged hard palate repair in non-syndromic BCLP patients using three planned operations to optimise the primary surgery.

**Methods:** Healing outcomes were retrospectively collected for 20 patients with non-syndromic BCLP who had been surgically managed by the senior author. All patients had their palates repaired using a three stage approach (cleft lip with unilateral vomer flap, contralateral vomer flap and palate repair).

**Results/Conclusions:** All patients healed without complication and to date, no fistulas have been observed or reported within this 20-patient cohort. Only one patient has required secondary speech surgery. Whilst small

numbers, this audit suggests a three stage approach may reduce dehiscence and fistula rate, with comparative or possibly improved surgical speech outcomes.



### **The 'Hidden' burden of the Cleft service**

**Maria Houlihan**<sup>1</sup>, Holly Peryer<sup>1</sup>, Hannah John<sup>1</sup>  
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**Background:** The UK has centralised regional multidisciplinary cleft services which cater to the needs of patients born with cleft lip and/or palate. Patients with non-cleft velopharyngeal dysfunction (VPD) are often referred to the cleft service to assess and manage speech concerns. These patients may then require multiple investigations, surgical intervention and have less predictable outcomes compared to patients with cleft palate. This study aims to identify the impact of non-cleft patients on the cleft service.

**Methods:** This was a retrospective cohort study of all patients who presented to the West Midlands cleft service from January 2020 to December 2023. The contributions of different clinical specialties and ancillary services to this cohort of patients were assessed and compared to those with a cleft diagnosis. The costs of the 'extra' investigations and cost- input of different specialties were analysed.

**Results:** During this 48-month period, 187 new patients were referred to the West Midlands cleft service, of which 15 had VPD without a cleft lip and/ or palate or a submucous cleft palate diagnosis. All 15 patients required surgical intervention. The different services involved in their care included surgeons, speech and language therapists, nurses, anaesthetics, genetics, respiratory physicians, and radiology. The pathway of care for a non-cleft VPD patient had a significant financial impact on the cleft service.

**Conclusions:** This is snapshot of the impact of non-cleft patients to a single cleft service. The assessment and management of non-cleft patients creates a significant burden to the cleft service. By quantifying this data, we highlight the 'extra' work we do, which can be used to guide service prioritisation in the NHS and help future workforce planning.



### **Social Media and Website Use: The experiences of parents accessing care at a Craniofacial Unit.**

**Sarah Kilcoyne**<sup>1</sup>, Sarah Overton<sup>1</sup>, Sally Brockbank<sup>1</sup>, Dr Samuel Lloyd-White<sup>1</sup>, Dr Rosanna Samuel<sup>1</sup>, Dr Matthew Hotton<sup>1</sup>, Gregory Thomas<sup>1</sup>, Rosanna Ching<sup>1</sup>, David Johnson<sup>1</sup>  
<sup>1</sup>Oxford Craniofacial Unit

Historically, medical professionals have been the providers of specialist information about rare medical conditions. Now, increasingly, patients and the public are using the internet to access and generate information about medical diagnoses. This research investigated the use of website and social media in parents of children with craniosynostosis.

**Methods:** A cross-sectional survey-based design was employed. Participants were parents of children with craniosynostosis attending multidisciplinary craniofacial clinics within the Oxford Craniofacial Unit. A questionnaire was administered which assessed social media and website use over an 18-month period (November 2020 – May 2022).

**Results:** The final sample comprised 82 parents (70 mothers; 10 fathers; 1 sister/carer and 1 parent [mother/father unspecified]). The children were aged 11 months – 16 years of age (average age 6 years 3 months). Children had a variety of diagnoses: 31 sagittal, 19 metopic, 14 syndromic craniosynostosis, 8 unicoronal, 6 multisuture, 3 bicoronal, and 1 unilambdoid.

Results showed that 93% (n=76/82) of parents used the internet to find out more about craniosynostosis, with 72% (n=59/82) of parents specifically using social media to find out more about craniosynostosis. The social media platforms used included: Facebook 64% (n=53/82), Instagram 24% (n=20/82), Blogs 12% (n=10/82), Twitter 4% (n= 4/82), Tik Tok 2% (n=2/82), and Snapchat 0.01% (n=1/82).

Parents reported that Facebook was the most helpful source of information about craniosynostosis (52%: n=43/82). Parents indicated the key timepoints they used social media included: when their child received a

diagnosis (70%: n=58/82), before their child's surgery (34%: n=28/82), before their first craniofacial clinic appointment (83%: n=25/30), and when child was older (17%: n=14/84).

Conclusion: Results highlight that parents use social media and other websites to access information relating to craniosynostosis. Future research should examine whether parental use of social media changes across their child's lifespan and evaluate the quality of this information.



## **Mobile applications in cleft care: is the UK behind?**

**Henry de Berker**<sup>1</sup>, Clare Rivers<sup>2</sup>

<sup>1</sup>Manchester University NHS Foundation Trust, <sup>2</sup>Leeds Teaching Hospitals NHS Trust

Background: Ninety-eight percent of the UK's (UK) adult population have a mobile phone. Globally, there are more mobile phone subscriptions than people on the planet. Mobile applications (apps) have a growing utility in healthcare; harnessing this technology can provide a range of functions including training, patient education, and follow-up.

Aims: To establish what apps dedicated to cleft care are currently available globally, and whether there is any evidence that they are being routinely used in practice in the UK.

Methods: The following sources were used to identify the use of apps in cleft care: presentations from the previous 3 conferences of the American Cleft Palate Craniofacial Association (ACPA), Craniofacial Society of Great Britain & Ireland (CFSGBI) and the 2022 Cleft Congress; PubMed; and the Google Play (Android) and iOS (Apple) app-stores.

Results: We identified 16 apps being used in cleft care globally. The majority of apps were developed in the United states (63%), and none were reported as being used in the UK. Applications were most commonly used for data collection and patient education (both 25%). Most of the applications were aimed at patients (44%), followed by clinicians (38%). There are currently 8 cleft-specific apps available in the UK to download onto iOS, and only 4 available to download on Android. Two of the applications available in the UK are in foreign languages (Arabic and Filipino). of the 10 apps identified in presentations/literature, only 2 are available in the UK.

Conclusion: There are a range of apps specifically designed to be used in cleft care. However, only half are available in the UK. Additionally, there is no published evidence that these applications are currently part of routine practice; a national survey may provide more information. The development of UK-specific cleft care apps might improve cleft care in the UK.



## **Cleft Lip and Palate Educational Video Series for Students**

**Bhavika Khara**<sup>1</sup>, Shonnely Novintan, Kaeli Cowling, Tim Goodacre

<sup>1</sup>University Hospitals of Leicester

Background: Recent studies have identified suboptimal knowledge and involvement in the care of those with, and caring for, cleft lip and palate (CLP) related disorders. This includes many studying for higher qualifications in medicine, nursing, and allied health care disciplines. Such lack of even a reasonable overview of best practice in cleft care, including multi-disciplinary management, has undoubted detrimental effects in delivering the highest standards of care across all aspects of the community.

Aims & Objectives: Our aim is to offer a major improvement in educational resources available to undergraduate students, trainees and healthcare professionals to improve understanding of CLP conditions. It is hoped that this might improve national CLP standards for early diagnosis and other aspects of best care within an integrated health care system.

Methods: A video series has been made, employing a combination of short presentations, combined into episodes that each cover an important aspect of cleft care. A total of 6 episodes have been written and delivered in a short video format so that engagement and understanding can be optimised on various social media platforms. At the conclusion of each episode, there is a reading list, reference list, and a short set of single best answer questions to test and consolidate knowledge. Episodes are released regularly, and are freely available to trainees and the wider public, along with an interactive survey to facilitate progressive improvement.

Conclusions: The CLEFT Education Video Series will enhance education around cleft lip and palate care by offering practical, experiential learning. Through the blend of expert insights and real-life scenarios, we aim to empower the next generation of cleft trainees, MDT members and health care professionals involved in the care of these patients, as well as those in other disciplines who might occasionally come into contact with CLP patients.



### **Interpretation of nasalance scores obtained from Nasality Microphone**

**Laura Lund Kuhlmann**<sup>1</sup>, Kirstine Bagger Kristensen<sup>1</sup>, Pernille Hartmann Pedersen<sup>1</sup>, Maria Boers<sup>1</sup>, Signe Angermann<sup>1</sup>

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Background: The commonly used nasality device, Nasometer 6450 from KayPentax, is currently inaccessible in many European countries due to EU import restrictions. Introducing a new nasality device for nasality assessment requires knowledge on the comparability to other nasality devices and insights into the validity of the instrument. In the search for an alternative nasality device, the Nasality Microphone from RoseMedical has shown to be comparable to Nasometer 6450 (Kuhlmann et al. 2022). The present study aims to provide basis for the interpretation of nasalance scores obtained from Nasality Microphone by means of:

1. Investigating correlations between nasalance scores obtained from Nasality Microphone and subjective auditory ratings of hypernasality performed by experienced SLPs.
2. Determining cut-off values for identifying hypernasality from nasalance scores obtained from Nasality Microphone.

Methods: Data was retrospectively collected from 56 participants aged 5 to 21 years. Participants were patients at Copenhagen Cleft Palate Centre due to a cleft palate or a VPI diagnosis. Data included nasalance scores obtained from Nasality Microphone and an auditory recording of spontaneous connected speech. Hypernasality was rated by two experienced listeners from the cleft team using a 5-point scale described in Lohmander et al. (2009). Intra- and interrater agreement were calculated.

Results: Preliminary analyses show a moderate positive linear correlation between hypernasality rating and nasalance scores. Different cut-off values are to be analyzed.

Discussion and conclusions: Nasalance scores obtained from the Nasality Microphone do to some degree reflect the auditory perception of hypernasality, however, the instrumental measure does not fully reflect the auditory rating. Possible factors affecting the correlation will be addressed. Nasality Microphone is an appropriate nasality device for use in cleft speech clinics, however, nasalance scores should be interpreted with regard to its limitations. Possible cut-off values will be discussed.

References:

Lohmander et al.(2009). CPCJ, 46(4).

Kuhlmann et al.(2022) [Poster].



### **The management of non-cleft patients presenting with absent or reduced soft palate movement**

**Dr Mena Al Whouhayb**<sup>1</sup>, Hannah Chandler<sup>2</sup>, Kana Miyagi<sup>1</sup>

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Introduction/Background: Some patients present with issues related to reduced or absent soft palate movement to cleft-services without an underlying diagnosis of cleft palate (CP) or cleft lip and palate (CLP). Currently, there is limited information available on management and outcome of such cases and there is no general consensus.

Aims/Objectives: Identify incidence of non-cleft patients presenting with absent/reduced palate movement, associated underlying conditions, management and clinical outcome.

Methods: Retrospective analysis of patients presenting to a regional cleft service with reduced or absent soft palate movement between 01/01/2015-07/11/2023 in the absence of CP/CLP. Patients were identified through search of EPICTM (patient-database). Patients with CP/CLP, submucous CP or those with short but normally moving palate were excluded. Data were analysed with focus on study objectives.

Results/Conclusions: A total of 10 cases were identified. Age at presentation ranged between 8-28yrs with median age of 11.5yrs (female:male=7:3). All patients presented with symptoms of velopharyngeal dysfunction (VPD). Half had diagnoses of genetic mutation or syndromes (including individual patients with Au-Kline syndrome, 22q11.2-deletion syndrome, KBG syndrome, chromosome 18p-deletion syndrome and myotonic dystrophy, respectively); further individuals had myasthenia gravis and ischaemic stroke, respectively.

All patients received speech and language therapy (SLT), 2 were referred to local SLT for support with total communication approach only, Eight received intervention from cleft and community services,. Six of the 10 had structural management; two had a non-operative device (NOD), two had Hynes-pharyngoplasty, one had a NOD followed by Hynes-pharyngoplasty, and one had a Hynes-pharyngoplasty followed by NOD. Mean treatment duration was 3.92yrs (range 2 months- 7 years)

Speech improvement was reported in 60% of patient notes with pending follow-up for 20% and 20% reporting no improvement.

Overall, our data suggest that a combination of SLT, NOD and surgery are required to attain improvement in patient outcomes in this complex patient-group.



# Free Paper Session 3 - Team Work & Surgery

## Diversity in Cleft Care for Great Britain and Ireland – Why it matters

**Matt Fell**<sup>1</sup>, Ambika Chadha<sup>2</sup>, Kanwalraj Moar<sup>2</sup>

<sup>1</sup>Spires Cleft Centre, Oxford, UK, <sup>2</sup>Cambridge University Hospitals, Cambridge, UK

Background: Patients born with a cleft are inherently diverse and there is recognition that access to elements of cleft care, such as speech therapy in the community, dental care and returning adults is not currently universal. Although, at its core, diversity from a demographic perspective is the practice of including and involving people from all backgrounds, it can also be viewed from a cognitive perspective, which involves the inclusion of people who think and problem solve differently.

Aims and Objectives: Look for current best practice and develop a meaningful diversity strategy for CFSGBI.

Methods: Literature regarding diversity in clinical and non-clinical settings was reviewed. Diversity policies and strategies published by healthcare societies and Royal Colleges were scrutinised. The CLAPA diversity and inclusivity committee was contacted for advice.

Results/Conclusions: Three main themes are presented for further discussion to generate momentum in this field:

1. Integrate diversity within the cleft agenda alongside clinical outcomes, audit and research. Develop a CFSGBI diversity position statement (as per other specialist associations and Royal Colleges), a dedicated section on the website and discussion at the scientific conference, in co-production with service users.
2. Encourage research relating to diversity in cleft care to understand inequalities and discrimination that exists amongst both patients and professionals.
3. Promote awareness of diversity and challenge unconscious bias via educational resources across both professional and patient groups.

Both demographic and cognitive diversity are highly relevant to the complex challenges faced by the cleft community. Cleft care in Great Britain and Ireland has many attributes for which it can be truly proud, but our care must continually evolve as we strive to elevate standards. Wholeheartedly embracing diversity at this opportune moment will help to achieve this, for the benefit of patients and healthcare professionals alike.



## Adult Cleft Care Pathways

**Dr Rebecca Crawford**, Dr Katherine Berlouis<sup>1</sup>

<sup>1</sup>NHS Scotland, Glasgow, Scotland

Background: Standard input for people in UK Cleft Services is often completed between the ages of 15-20: all interventions post alveolar bone graft are elective. Adults can return for additional care at any point; many may not currently be under an NHS Cleft Team, have been discharged, or treatment took place before Cleft Teams existed.

Notably, there is significant variation in adult referral pathways and resource provision across UK Cleft Centres. The National Cleft Surgical Service for Scotland (NCSSS) present data from their Adult Cleft Care Pathway, with the ambition of considering more standardised practice across the UK.

Methods: The NCSSS mandates all returning adults have a 60 minute (minimum) 1:1 in person appointment with a Cleft Clinical Psychologist, with a screening questionnaire (Adult Assessment Pack) sent out in advance. This system aims to elicit cleft related issues from the patient perspective.

Results: Key themes from completed adult initial assessments included;

1. Current cleft related issues
2. Cleft experience - including previous interventions
3. Timing of request for intervention
4. Full mental health assessment
5. Expectations/hopes for future intervention

Discussion: The NCSSS Adult Cleft Care format appears to be favoured by both patients and clinicians. Psychology is impartial with regards to proceeding with intervention, with more collaborative care resulting in

higher satisfaction of intervention for patients. Other advantages of pathway included; assurance of patient psychological stability, establishing what is cleft related and what is not, as well as accurate level of adult demand and capacity required.



## **A case series of borderline Velopharyngeal Dysfunction: the importance of Psychological weighting in management.**

**Hannah Chandler**<sup>1</sup>, Karine Edme<sup>1</sup>, Ambika Chadha<sup>1</sup>

<sup>1</sup>Cambridge University Hospital NHS Foundation Trust [Cleft.NET.East], Cambridge, UK

Background: As per the NHS contract, UK cleft services treat velopharyngeal dysfunction (VPD) originating from both cleft and non-cleft pathology. Both pathologies may present with borderline/mild/marginal velopharyngeal dysfunction (VPD).

In cases of marginal velopharyngeal dysfunction (VPD) often surgery is not proposed and a 'watch and wait' approach is recommended. This decision is generally based on clinician judgement of severity and low perceived risk/benefit analysis.

However, a small group of patients' present with severe psychological distress in reaction to their perceived speech differences, impacting significantly on their quality of life.

There is no protocol that enables a variable weighting in the psychological assessment of such patients to inform a decision for surgery.

Aims: We present a series of 3 recent cases where surgical intervention has made a significant impact on psychological outcomes for the given improvement in speech-related outcomes.

In all cases, we consider that the relatively modest change in palate anatomy effected by surgery has led to a disproportionate improvement in psychological outcomes.

All presented with normal resonance, inconsistent mild inaudible emission and normal/touch closure. After consideration, for many years and by multiple centres in some cases, surgery was offered. Post-operative feedback described how surgery "changed life", "made a huge difference" and "was worth it" as the distress around perceived VPD experienced by patients' had resolved.

Conclusion: These cases highlight the significant impact that can be made by offering surgical management in cases presenting with 'borderline' VPD but high psychological distress.

We propose that the cohort of patients with objectively mild VPD may have unique subjective needs and that a weighted psychological assessment should be used in clinical decision making.

Our case series exemplifies the important role that patient experiences, preferences and values have in shared decision-making and adds to the body of literature in this field.



## **Speech outcomes from secondary surgical intervention for Velopharyngeal Dysfunction**

**Christopher Blore**<sup>1</sup>, Louise Cafferky<sup>1</sup>, Neil Brierley<sup>1</sup>, Khurram Khan<sup>1</sup>

<sup>1</sup>West Midlands Regional Cleft Centre, Birmingham, UK

Background: Cleft palate repair aims to create acceptable palatal form and function. There is, however, a recognised cohort of patients with suboptimal speech outcomes following initial repair in which surgical revision procedures are required to alter anatomy. Similarly, in non-cleft velo-pharyngeal dysfunction (VPD), surgical intervention is sometimes required to optimise speech.

Aims & objectives: To investigate the speech outcomes and surgical complications of all revisional surgery for both cleft VPD and non-cleft VPD in a cleft regional centre.

To assess each palatal or pharyngeal intervention to identify speech improvement achieved.

Methods: A single site, multiple surgeon retrospective review of speech and surgical outcomes in a single cleft regional centre over a 3 year period. For cleft patients the type of cleft and primary repair method was recorded, as well as presence or absence of fistula. Lateral video fluoroscopic findings were recorded for all patients. Post-operative speech assessments were carried out at a minimum of 6 months following surgery. Speech data from pre- and post-operative assessments was collected and analysed.



Results/Conclusions: 70 patients underwent secondary surgical procedures for speech, at between 2 and 16 years of age. 42% of cases were for isolated cleft palate, 21% for bilateral cleft lip and palate, 16% were unilateral cleft lip and palate whilst submucous cleft and non-cleft VPD each contributing around 10% of cases. 23% of cases had an identified genetic or syndromic element. Palatal revision included Furlow palatoplasty, IVVP re-repair and buccinator flap lengthening. Pharyngeal procedures included dynamic and static pharyngoplasty. All surgical interventions were shown to give a variable improvement in velopharyngeal function, but there was no statistically significant difference between the procedures.



## **A descriptive framework for the provision of specialist therapy for individuals with palate-related speech difficulties**

**Dr Samantha Calladine**<sup>1</sup>, Tanya Pipkin<sup>1</sup>

<sup>1</sup>Leeds Teaching Hospitals NHS Trust

Background: The national service specification for cleft palate and velopharyngeal dysfunction (NHS England, 2013) specifies that speech and language therapy (SLT) is delivered by both local and regional specialist SLT services. However, there is insufficient detail about each service's remit. Within the managed clinical network of the Leeds cleft unit, this has caused confusion around who should be providing care and inequities in provision around the region. A qualitative service development project was undertaken to address this.

Aims:

1. To provide a detailed description of the service-wide, regional therapy provision and systems in place to monitor and evaluate outcomes
2. To ensure consistency and equity in the delivery of specialist therapy across the caseload
3. To ensure specialist therapy provision is based on best available evidence

Methods: The project adopted a practice-based approach. A cross-sectional analysis was undertaken of the regional therapy caseload to identify themes relating to the aims and objectives of therapy. These were categorised into different packages of care set within a tiered framework. The framework was refined through regular whole team discussions and in collaboration with community link SLTs. The current evidence for speech intervention was reviewed to produce an evidence-based description of each package of care, including entry and exit criteria, therapy aims, and dosage.

Results and Conclusions: The project has produced a detailed description of the specialist therapy provision provided by the Leeds cleft unit for children and adults with palate-related speech difficulties. It provides clarity on the remit of the specialist service, point of transfer to/from community SLT services, and how these services will work together to provide shared care. The framework supports consistency and equity in service delivery and provides a basis for monitoring and evaluating the provision and effectiveness of therapy.



## **Comparative analysis of a dramatic change in protocol for patient attendance at CLPMDT clinics**

**Dr Sean Daley**<sup>3</sup>, Dr Sasha Brannen<sup>3</sup>, Dr David Landes<sup>2</sup>, Dr Rye Mattick<sup>1</sup>

<sup>1</sup>Newcastle Site of Northern and Yorkshire Clp Service, Newcastle upon Tyne, UK, <sup>2</sup>Dental Public Health, NHS England NE and Yorkshire, UK, <sup>3</sup>Newcastle upon Tyne Hospitals NHS Trust, Newcastle upon Tyne, UK

Background: During COVID the opportunity arose for the Northern and Yorkshire (Newcastle) team to redesign treatment pathway protocols: focussing key stages for face to face MDT clinic appointments (by lead clinicians triaging progress of all patient's pathways at set ages) and pulling all spoke clinics in to the hub. This comparative analysis focusses on the impact on patients/families and clinicians, and is part of a larger capture of the full scope of changes in healthcare delivery

Aims & Objectives: We aim to compare the number of patient episodes and any potential change in time off school/work for families between the 2 pathways. Assessment of the impact of changes on clinical resource utilisation will be considered. Insights gained will help to further refine the new protocols and service delivery.

Methods: MDT clinic appointments for hub and 5 spoke clinics for 3 months in 2019 will be used. The new protocols will be applied to those same patients to see if they would now still have been sent for at the hub MDT. Using a

comparative 3-month period in 2023 clinical activity of those that would have travelled to spoke clinics will be assessed.

Comparative analysis will allow us to understand the shift in Cleft team practices and their effectiveness.

Results: It is anticipated that:

Unfocussed patient attendances have been reduced

Clinical travel time is now utilised providing direct CLP patient treatment episodes



## **How patients and cleft teams can work together to improve the return to treatment process**

**Gillian McCarthy**<sup>1</sup>, Claire Cunniffe<sup>1</sup>

<sup>1</sup>CLAPA - Cleft Lip and Palate Association, London, UK

Background: The Whole of Life Survey research (Ardouin et al 2020) findings suggest even adults aware of NHS care entitlement struggle to access this via GP or Dentist referrals. This appears to still be the case in 2023. What should be a relatively straightforward process is often turned into a complicated and emotional process resulting in patients seeking out private options or accepting they will not access further treatment.

CLAPA is working closely with the Cleft Community to understand and improve the experience of adults returning to NHS cleft treatment. In May 2022 CLAPA started a Patient Engagement Group for the Cleft Development Group (CDG PEG). This group have been championing self-referral for adults returning to treatment in cleft teams. We discuss the progress they are making.

Aims & Objectives: To have a better understanding of adults experiences when attempting to return to the NHS for Cleft treatment.

Methods: Using data from the CLAPA Annual Survey 2023 and the lived experience of adults born with a cleft lip and/or palate who have experienced returning to Adult NHS Cleft Treatment.

Results/Conclusions: Cleft teams are open to improving their processes for adults returning to treatment. We share the progress made to date.

References (author and year): CLAPA Annual Survey (2023); Treatment Experiences in Adults Born With Cleft Lip and/or Palate: A Whole of Life Survey in the UK (2020) Ardouin et al



## **Mother's Health during pregnancy and the development of Orofacial Clefts**

Anni Christou<sup>1</sup>, **Amy Davies**<sup>2</sup>, Prof Sarah Lewis<sup>1,2</sup>

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Background: Non-syndromic orofacial clefts have a multifactorial aetiology. Throughout the first weeks of gestation a combination of factors, including maternal health, can impair and disrupt craniofacial development potentially leading to the formation of an orofacial cleft. Maternal asthma, diabetes and hypertension have all been associated with an increased risk of congenital malformations in offspring, including orofacial cleft.

Aim: Determine whether there is an association between maternal asthma, diabetes and hypertension with the development of orofacial clefts in offspring.

Methods: Data from the Cleft Collective were used to determine the percentages of mothers, in a cleft population, who had ever been diagnosed with asthma, diabetes or hypertension. Publicly available data were used to determine the percentage of people who had ever been diagnosed with these conditions in the general population. General population figures for asthma were restricted to people aged between 16-50 but did include males. General population figures for diabetes and hypertension were restricted to women aged between 16-44. Disease rates were compared between the cleft and general populations to determine odds ratios and identify whether associations between these health conditions and orofacial cleft in offspring were present.

Results / conclusions: Past or current diagnoses of asthma, diabetes or hypertension were reported within 19.8%, 4.1% and 5.6%, respectively, of mothers within the Cleft Collective. Preliminary analyses suggest an increased

rate of both asthma and diabetes within the cleft sample compared to the general population. However, further investigation is needed and more granular general population data is being sought. Full analyses will be presented at the conference.



### **Transferable lessons from a health-worker led congenital anomaly screening program in Pakistan**

Dr Shazia Moosa<sup>1</sup>, Dr Mahwish Fatima<sup>1</sup>, Dr Mahnoor Nawab<sup>1</sup>, **Dr Felicity Mehendale<sup>3</sup>**, Dr Lubna Samad<sup>2</sup>  
<sup>1</sup>IRD Pakistan, Karachi, Pakistan, <sup>2</sup>IRD Global, Singapore, Singapore, <sup>3</sup>Centre for Global Health Research, Usher Institute, The University of Edinburgh, Edinburgh, Scotland

**Background:** The burden and mortality due to congenital anomalies is significant with few surveillance systems or care pathways in place in lower- and middle-income countries. Timely referral leading to early interventions reduce disease burden.

**Aims & Objectives:** We present our initial experience of a health-worker led surveillance program in Pakistan, that aims to bridge the existing health system gap.

**Methodology:** Curriculum development: Educational and data collection tools were developed and translated in regional language (Urdu). Counseling guidelines and referral pathways were developed with expert input.

**Health worker training:** A two-week structured educational intervention was conducted to train health workers to screen neonates for external congenital anomalies which included basic subject knowledge, neonatal examination, psychologist-led sessions on counseling families, data collection and entry. This was followed by a two-week on-site pilot phase. Structured knowledge assessment was conducted.

**Implementation:** Newborns are enrolled prospectively, all identified anomalies documented, and referral guidance provided. A follow-up call at the end of the neonatal period documents late-presenting anomalies, outcomes, and healthcare access patterns for recommended care, for each enrolled baby.

**Results:** 15 health workers underwent classroom training; 13 were selected for practical training. A statistically significant increase in median knowledge score was observed in the pre and post-test assessments (5.5 vs 18.0). Out of the 5,078 newborns screened till 30th November 2023, 1,174 (23.1%) had one or more congenital anomalies. Total number of anomalies identified were 1,395 of which 108 (8%) were classified as major and 1,281 (92%) as minor. Major craniofacial anomalies included orofacial clefts (n=9), encephalocele (n=3), microcephaly (n=2), anencephaly (n=1), and microtia (n=1). The concordance of anomaly diagnosis between health worker and photographic review by specialists was 93%.

**Conclusion:** Leveraging trained health workers to screen newborns for congenital anomalies is an effective strategy that has potential to result in early diagnosis and referral.



# Free Paper Session 4 - Dental/Ortho & Adults

## **The Implementation of intraoral scanners in evaluation and monitoring of growth outcomes in cleft patients**

**Andrew Stirrup**<sup>1</sup>, Maab Benashur, Trevor Hodge

<sup>1</sup>Leeds Dental Institute / Leeds Teaching Hospitals NHS Trust, Leeds, UK

**Introduction:** This quality improvement project, conducted at the Leeds Dental Institute, focuses on improving facial growth outcome data obtained at 5-years of age. Traditionally, these assessments are conducted using dental impressions or photographs, which can be challenging with young patients and even more so with patients who have behavioural difficulties. To address this, the introduction of intra-oral scanners has been utilised as an alternative.

**Aims and Objectives:** The primary aim of this project is to demonstrate the integration of scanners as an alternative from traditional techniques from a patient's, carer's and clinician's perspective. We also hope to demonstrate its feasibility of implementation and the benefits of intraoral scanner use for digitisation of growth assessments. The objective is to increase the completeness of records obtained with minimum distress to patients.

**Methods:** We conducted a retrospective study using archived data from 5-year cleft outcome clinics carried out between 2018 and 2023. The study included UCLP patients undergoing growth assessments. Of the remaining patients aged 5, we identified the number who tolerated dental impressions and those who underwent digital scanning.

**Results:** Of the evaluated individuals, dental impressions had a poorer uptake, while a larger proportion accepted intraoral scanning since its introduction. This demonstrates intraoral scanners are a feasible and implementable method for improving uptake and quality of arch assessments. Both clinician and carer qualitative feedback has been positive due to the less invasive nature of this method over impressions. Whilst there are limitations to intraoral scanners, its ability to produce a virtual model is superior to clinical photography in addition to the benefits of digital records.

Chalmers, E. et al 2016. Intraoral 3D scanning or dental impressions for the assessment of dental arch relationships in cleft care: which is superior?



## **Dental Access and Preventive Advice for Children with Cleft Lip and/or Palate by 12 months.**

**Dr Rachel Sladden**<sup>1</sup>, Dr Harriet Wilson<sup>1</sup>, Dr Reuben Bennett<sup>1</sup>, Dr Amy Hollis<sup>1</sup>

<sup>1</sup>University Hospitals Bristol and Weston NHS Foundation Trust, Bristol, United Kingdom

**Background:** Children with cleft lip and/or palate (CLP) are oral health priority patients, experiencing increased caries and dental anomalies. The British Society of Paediatric Dentistry's 'Dental Check by 1' (DCBy1) initiative advocates dental visits by 12 months. This audit assessed dental information provided to CLP patients under the South West Cleft Service (SWCS) by their first birthday and adherence to DCBy1 recommendations.

**Aims and Objectives:**

1. Establish information sources for oral health received by parents/carers.
2. Ascertain CLP patients' involvement with dental services by 12 months.

**Methods:** In the first cycle, telephone interviews were undertaken with parents/carers of 30 12-18 month olds under the care of the SWCS over a 4-month period. Following the introduction of telephone contact at 6 months, provision of a cleft dental information pack, and standard letter for General Dental Practitioners, data was collected for the second cycle of this audit from 16 parents/carers. A standardised proforma was completed and data was analysed in an excel spreadsheet.

**Results/ conclusions:** In the first cycle, 17% children had been seen by a dentist by 12 months, 43% had received toothbrushing advice, 33% had received diet advice and 81% had received a dental pack. In the second cycle, 21% had been seen by a dentist by 12 months, 71% had received toothbrushing advice, 71% had received diet advice and 100% had received contact from the SWCS dental team and received a cleft dental information pack.

The second cycle showed significant improvements, but challenges remain. Prioritising CLP patients and establishing a dental home are crucial for gaining access to dental care to help improve oral health.

References:

Haque S., Alam M.K., 2015.

Wells M., 2014.



## **Alveolar Bone Graft Outcomes in the North East of England: Timing of Dental Extractions**

**Sasha Brannen**<sup>1</sup>, CR Mattick, Rachel Goldsmith

<sup>1</sup>Newcastle Dental Hospital, Newcastle Upon Tyne, UK

Background: Patients about to undergo Alveolar bone grafting (ABG) may require dental extractions, for surgical access, caries, removal of supernumeraries or poor prognosis teeth or to preserve the airway. Extractions can be done ahead of the ABG procedure to maximise oral mucosal integrity, or at the time of surgery. Within the Northern site of the North and York Cleft Lip and Palate Service, extractions are carried out alongside the ABG surgery. Anecdotally, other areas of the UK undertake dental extractions in a separate procedure. Success of the ABG is evaluated radiographically approximately 6 months after the procedure.

Aims and Objectives:

To assess the outcome (Kindelan score) of all ABG's undertaken between January 2020 and January 2023

To ascertain whether dental extractions were required, the reason for extraction and subsequent timing of extraction.

To ascertain whether expansion was carried out.

Standard: To ascertain whether The Northern and Yorkshire Cleft lip and palate services meets a locally agreed standard success rate of Kindelan score grade 1 or 2 of 90%.

Methodology: A retrospective audit of the patient pool via the cleft data coordinator was used. Information was taken from electronic notes and inputted to MS Excel. Patients were excluded if Kindelan scoring was not available, or if the procedure was a repeat graft after failure.

Results/ Conclusion: 90 patients underwent an ABG procedure. 73 patients were included, with a total of 82 operated sites. 88% of patients achieved a grade 1 or 2 Kindelan score. Sixty-five out of 73 patients had dental extractions (89%). Sixty-four patients had extractions during the ABG surgery. Dental extractions at ABG surgery does not appear to influence ABG outcome and should be carried out at the time of ABG procedure.



## **Patient and Public Involvement in oral health inequalities research in children with a Cleft.**

**Madhavi Seshu**<sup>1</sup>, Dr Sondos Albadri<sup>2</sup>, Gillian McCarthy<sup>3</sup>, Susan Sajan<sup>1</sup>

<sup>1</sup>Alder Hey Children's Hospital, Liverpool, UK, <sup>2</sup>Liverpool University, Liverpool, UK, <sup>3</sup>Cleft Lip and Palate association, London, UK

Introduction: Health inequalities are one of the major barriers facing communities in UK, especially for disadvantaged groups and areas. Patient and Public involvement is the key to conducting patient-centric research. The COREPLUS5 approach taken by the government for children includes oral health to drive targeted action in healthcare inequalities improvement.

Aims and objectives: To achieve a collaboration between CLAPA, Parents, lay public, Alder Hey children's charity, researchers and NIHR for design of health inequalities research for children with a cleft. The objective was to focus on barriers to access dental care for children attending the Bone graft clinics in Alder Hey children's Hospital, Liverpool.

Methods: This research has a qualitative methodology, funded by NIHR and Alder Hey children's charity. PPI involvement was started before the submission of the research proposal. Focus groups was conducted with the help of CLAPA, which included parents whose first language was not English and from different socio economic backgrounds. A Visual aid was developed from the PPI focus group meeting to help research participants whose first language is not English.

Audio and written information sheets and consent forms in English/Welsh were made with PPI support and using a chatbot to achieve a reading age of 9 yrs. Technology including immersive reading was used to include parents regardless of their ability. Focus group interviews and PPI feedback was done thro videoconferencing platforms. Ethical approval process is ongoing after PPI focus groups (Wales REC /330971)

Conclusion: Collaboration with charities, parents, patients, lay public and researchers gives real-life context to health inequalities research. The issues raised by parents in focus groups regarding access to dental care depends on the inclusion of parents from different cultures, languages and socio economic groups. This inclusion can be facilitated by technology and collaboration with all stake holders.



## **The Effect of Buccal Flaps on Dentition in Patients Post Cleft Palate Repair**

**Susan Mccrossan**<sup>1</sup>, Eammon Francis<sup>1</sup>, Dr Fiona Graham<sup>1</sup>, Eoin O'Broin<sup>1</sup>

<sup>1</sup>Cork University Hospital, Cork, Ireland

Purpose: To assess the effect of the pedicle in one stage buccal mucosal flaps (for cleft palate repairs) on dental hygiene, access and posterior molar teeth eruption.

Patients and Methods: All patients who underwent a buccal mucosal flap by a single surgeon from 2008-2015 were retrospectively identified. Patient demographics included; cleft type, repair type and timing, indication for the buccal flap, whether flap was used for the nasal layer, oral layer or both, flap division and timing.

Exclusion criteria included cases who had the pedicle of their flap divided before dental review. A single paediatric dentist, documented presence of a buccal band, plaque score index, gingival probing depth, crown height and buccal sulcal depth.

Results: Twenty-seven patients had buccal flaps, 19 for primary palatal repair and 8 as a secondary repairs (3 for a fistula and 5 were for secondary speech issues).

Eight cases were excluded (n=5 already had their buccal flap pedicle/band divided before review and n=3 had incomplete data) leaving 19 patients for dental analysis.

The cleft types were "wide,secondary"(n=5), "UCLP"(n=4) and "BCLP"(n=2).

The presence of plaque on the buccal surface of the most distal molar tooth and the gingival probing depth is reported.

The crown height measurements varied from 2-7mm and were symmetrical (n=7) or within one millimeter of each other(n=4).

The depth of the buccal sulcus to the most distal upper molar tooth measurements varied from a difference between sides of 0mm(n=2), 1mm(n=5) and 2mm(n=4).

Conclusion: The buccal mucosal flap is a useful technique in palatal repair. The pedicle may sometimes form a band which may interfere with the posterior molars, requiring division. However, most cases require only one stage and appear to have minimal negative effects on dental hygiene, access and dental eruption.



## **The use of fixed and removable bite blocks in buccinator flap surgery for velopharyngeal insufficiency.**

**Dr Lucy Coull**<sup>1</sup>, Mary A Bussell<sup>1</sup>, Nefer Fallico<sup>1</sup>

<sup>1</sup>Salisbury District Hospital, Spires Cleft Centre, UK

Background: Buccinator flap surgery is widely performed for velopharyngeal insufficiency. The use of bite blocks to prevent post-operative pedicle injury from the occlusal surfaces of the molar teeth is an accepted practice, as is dividing the pedicles at a second stage. There is, however, no published literature on the current surgical practice regarding the use of bite blocks or pedicle division, nor any comparing the types of bite blocks or their complications.

Objectives: To ascertain the current practice in the UK with regards to the use of bite blocks and the division of the pedicles in buccinator flap surgery for velopharyngeal insufficiency. To compare the outcomes of fixed and removable bite blocks in buccinator flap surgery, in terms of the incidence of pedicle injury and patient experience.

Methods: Survey of cleft surgeons in the UK on their use of bite blocks and division of the pedicles. Retrospective cohort review of consecutive patients that underwent buccinator flap surgery at Salisbury District Hospital between

1/1/21 and 31/12/22 comparing the complications of fixed and removable bite blocks. Survey of patients who had bite blocks fitted to understand the patient and family experience.

Results/Conclusions: Cleft consultants from all units in the UK and Northern Ireland responded: half (11 out of 22) reported using bite blocks and half reported routinely dividing the pedicles, most commonly at 4 to 6 weeks after surgery. In our cohort (19 patients), fixed bite blocks had a higher incidence of pedicle injury (33%) and difficulty eating (78%) than removable bite blocks (20% and 20% respectively). Generally, parents/patients tolerated the presence of bite blocks and were often unaware of pedicle injury, even in cases of repeated severe biting. Overall, bite block use varies between surgeons and fixed bite blocks may be associated with higher complication rates than removable bite blocks.



## **Transition to Adult NHS Cleft Treatment (The Patient Perspective)**

**Becky Croft**<sup>1</sup>, Claire Cunniffe<sup>1</sup>

<sup>1</sup>CLAPA - Cleft Lip and Palate Association, London, UK

Background: The transition from being a child to an adult under NHS care for a lifelong condition such as cleft is a time full of change. Research suggests that all young adults about to end routine treatment should have information made available to them to ensure they are aware of the services available as well as how to access these (Ardouin et al 2020). The Whole of Life Survey research (Ardouin et al 2020) suggests even adults aware of NHS care entitlement struggle to access this via GP or Dentist referrals. Our community (ages 16-24) tell us about their experiences and issues accessing NHS services, top concerns about their cleft care and issues seeking a referral to NHS Cleft Teams.

Aims & Objectives: To have a better understanding of the needs of young adults and transition experiences.

Methods: Using data from the CLAPA Annual Survey 2023 and the lived experience of young adults born with a cleft lip and/or palate who have experienced the transition from children to adult NHS Cleft Treatment.

Results/Conclusions: The main issues for young adults seeking a referral were long waiting times, lack of communication, and referrals being refused due to cosmetic issues. Top concerns about cleft care were their or their partner's emotional wellbeing, dental health and access to NHS dentistry, and long wait times for appointments. There are changes which could support this transition, such as self-referral, improved communication and the CLAPA 'Returning to Cleft Care' pack.

References (author and year): CLAPA Annual Survey (2023); Treatment Experiences in Adults Born With Cleft Lip and/or Palate: A Whole of Life Survey in the UK (2020) Ardouin et al



## **Adult UK Cleft Care Pathways: Standardisation Across the UK**

**Dr Katherine Berlouis**<sup>1</sup>, Dr Rebecca Crawford

<sup>1</sup>NHS Greater Glasgow and Clyde, Glasgow, Scotland

Background: Standard input for cleft patients in the UK is completed between the ages of 15-20: all interventions post alveolar bone graft are elective. Adults can return for additional care at any point; many may not currently be under an NHS Cleft Team, have been discharged, or treatment took place before Cleft Teams existed.

Notably, there is significant variation in adult referral pathways and resource provision across UK Cleft Centres. The National Cleft Surgical Service for Scotland (NCSSS) present data from their Adult Cleft Care Pathway, with the ambition of propagating standardised practice across the UK.

Methods: The NCSSS mandates all returning adults have a 60 minute (minimum) 1:1 in person appointment, with a screening questionnaire (Adult Assessment Pack) sent out in advance. This system aims to elicit cleft related issues from the patient perspective.

Results: Key themes from completed adult initial assessments included;

1. Cleft experience - including previous interventions
2. Timing of request for intervention
3. Full mental health assessment
4. Expectations/hopes for future intervention

Discussion: The NCSSS Adult Cleft Care format appears to be favoured by both patients and clinicians. Psychology is impartial with regards to proceeding with intervention, with more collaborative care resulting in higher satisfaction of intervention for patients. Other advantages of pathway included; assurance of patient psychological stability, establishing what is cleft related and what is not, as well as accurate level of adult demand and capacity required.



## **Green & good: Assessing the Sustainability of Virtual Clinics at Royal Manchester Children's Hospital**

**Tara Bharadia**<sup>1</sup>, Victoria Beale<sup>2</sup>

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Background: 1 in 700 babies in the UK are born with a cleft lip and/or palate (CLP). These patients are managed by a multidisciplinary team in less than 20 highly-specialised units in the UK. The high volume of patients and changes to clinical practice during COVID-19, led to the introduction of a virtual cleft clinic at the Royal Manchester Children's Hospital (RMCH). The trust which RMCH sits under, calculated that patient and visitor travel amounted to 66 million miles driven by an average petrol car. As part of their initiatives, they are looking to reduce patient journeys by introducing more digital patient appointments. This presentation delves into a comprehensive service evaluation at Royal Manchester Children's Hospital (RMCH), focusing on the sustainability and impact of their virtual cleft clinic.

Aims: The service evaluation aimed to assess the virtual clinic's sustainability through patient feedback, staff experiences, and environmental impact. While face-to-face appointments resumed for younger patients, virtual cleft clinics persist for secondary school-age children and young adults.

Methods: The evaluation utilised patient and staff feedback questionnaires, alongside a carbon measurement analysis to quantify the environmental impact. Over a 12-month period, virtual cleft clinics saved an estimated 2088 miles.

Conclusions: Patients provided favourable feedback, while staff expressed concerns about the efficacy of certain virtual appointments. Despite challenges, virtual cleft clinics emerged as a sustainable alternative, reducing both environmental and personal impacts associated with conventional face-to-face visits. This service evaluation offers insights into the evolving landscape of cleft care, showcasing how virtual clinics can enhance accessibility, minimise environmental impact, and meet diverse patient needs.



## **12 years of Cleft Orthognathic Surgery; Assessing Changes in Outcomes & Approach over time.**

**Junaid Rashid**<sup>1</sup>, Christopher Blore<sup>1</sup>, Ian Sharp<sup>1</sup>

<sup>1</sup>University Hospitals Birmingham, Birmingham, UK

Background: Orthognathic surgery often represents the final surgical intervention for cleft patients with residual dentofacial and skeletal discrepancy. The complication rates and outcomes in cleft orthognathic surgery have been previously described in our centre (1). With further years of data within a single centre, have complications and outcomes changed over time, how have they changed and why?

Aims/Objectives: To assess the outcomes and complications for all cleft patients undergoing orthognathic surgery in a single UK (UK) cleft centre.

To compare this cohort with previously published outcomes in the same centre and identify changes in trends and why such changes may have occurred.

Methods: Retrospective assessment of adult patients over 7 years from 2016-2022 in a single UK cleft centre, treated by a single Maxillofacial surgeon. Review of case notes, speech assessments, emergency attendances and correspondence documents for complications. Comparison with 2010-2015 cohort in the same centre, operated on by same single Maxillofacial surgeon.

Results/Conclusions: 45 cleft patients underwent orthognathic treatment between 2016-2022 compared with 79 in the previous study. Distraction osteogenesis was performed for 1 patient (2%) compared to 10 patients (13%) previously. The most common orthognathic procedure was conventional Le Fort 1 osteotomy (n=34) and the average anterior-posterior movement of the osteotomies was 6.3mm (range:2-10mm). These are smaller movements than previously described (2-18mm). The smaller average movement required may reflect improved



primary cleft surgery outcomes. Temporary neurosensory disturbance and speech discrepancy remain the most common complications. Overall complication rates remain acceptable. The global pandemic, along with disrupted local orthodontic services and hospital bed pressures are likely contributing factors to the complications recorded. Monitoring of outcomes remains important for safe orthognathic cleft care.

References: 1.Moran I, Virdee S, Sharp I, Sulh J. Postoperative complications following Lefort 1 maxillary advancement surgery in cleft palate patients *The Cleft Palate-Craniofacial Journal* 2017;55(2):231–7.



# Arnold Huddart Prize Session

## Surgical Waste in Cleft Lip and Palate Surgery

**Dr Muireann Keating**<sup>1,2,3</sup>, Dr Catherine De Blacam<sup>1,2,3</sup>

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Background: Hospitals produce large volumes of waste, 30% of which is generated from operating rooms. The aim of this study was to calculate the waste generated by cleft lip and palate (CLP) procedures and to increase awareness of the environmental impact of our specialty.

Methods: We performed a surgical waste assessment of 5 CLP procedures performed by a single surgeon in November and December 2023. Waste was divided into 5 streams based on the local hospital waste management system: recycling, non-recycling, laundered linens, sharps and biohazard. The weight of each stream was recorded.

Results: The average amount of waste (excluding laundered linens) generated per cleft lip and palate surgery was 5.5kg, of which 1.8kg (33%) was non-recycling waste, 2.1kg (38%) was recycling, 1.1kg (20%) was biohazard and 0.5kg (9%) was sharps. However the amount of waste recycled varied with one procedure with the same set up only 744g (15.1%) of waste being recycled. A study of surgical waste in total knee arthroplasties showed that 13.3kg of waste was produced per procedure, with only 0.3kg (2.2%) of this being recyclable. Similarly, a study examining surgical waste from hysterectomies demonstrated only 4 – 8% of the waste produced was recyclable. However, improvements still can be made, with variations on the amount waste recycled evident within our own study group.

Conclusion: Results demonstrated that the majority of waste produced by CLP procedures was recyclable. In comparison to studies of other specialties this is a significantly better than figures reported from other specialties. Awareness of procedure-based waste output is the first step in designing environmentally friendly waste management strategies.



## Are left sided orofacial clefts a different entity to right sided orofacial clefts?

**Matt Fell**<sup>1</sup>, Dr Kate Fitzsimons<sup>2</sup>, Amy Davies<sup>3</sup>, Dr Daniel Bradley<sup>4</sup>, Ambika Chadha<sup>5</sup>, Sophie Butterworth<sup>2</sup>, Dr Mark Hamilton<sup>6</sup>, Jibby Medina<sup>2</sup>, Dr Hussein Wahedally<sup>2</sup>, Dr Min Hae Park<sup>2</sup>, Prof Jan Van Der Meulen<sup>2</sup>, Bruce Richard<sup>7</sup>, Craig Russell<sup>6</sup>, Prof Yvonne Wren<sup>3</sup>, Prof Sarah Lewis<sup>3</sup>, Associate Prof David Chong<sup>8</sup>

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Background: The prevalence of left unilateral cleft lip with or without cleft palate (UCL/P) is consistently observed to be twice that of right UCL/P, yet it is not known whether the two represent different underlying phenotypes.

Aims and Objectives: To assess the co-occurrence of sidedness in unilateral cleft lip only (UCLO) and unilateral cleft lip and palate (UCLP) with additional diagnostic features.

Methods: A multimodal approach:

1. Scoping review of UCL/P sidedness in literature databases.
2. Data linkage of CRANE database to Hospital Episode Statistics (HES) to investigate association between UCL/P sidedness and additional congenital anomalies.
3. Cleft Collective parental questionnaires from birth and 5-year cohorts to assess association between UCL/P sidedness and additional comorbidities.

Results/Conclusions: The scoping review included 12 studies relating to the co-occurrence of UCL/P sidedness, which focused on dental anomalies, handedness, and congenital anomalies. There was a trend for right UCL/P to represent a more severe phenotype.

The CRANE data linkage included 3,788 children and reported a greater prevalence of additional congenital anomalies for right compared to left UCLP (32% vs 23%, OR 1.54, 95% CI 1.25 to 1.90: p<0.001). There was no evidence for a difference in the prevalence of additional congenital anomalies by sidedness in the UCLO phenotype.

The Cleft Collective data included 447 children and reported increased prevalence of vision anomalies for right compared to left UCLP (11% vs 3%, OR 3.68, 95% CI 1.22-11.13; p=0.021). There was no evidence for a difference in vision by sidedness in the UCLO phenotype.

These findings challenge previously held beliefs that UCL/P sidedness is simply an administrative feature for classification purposes alone and instead suggest that left and right are distinct entities and furthermore are different for UCLO and UCLP phenotypes. Future work to improve understanding requires adequately powered GWAS and DNA sequencing studies.



## Exploring Barriers to Cleft Training in the UK

**Shonnely Novintan**<sup>1</sup>, Brian Sommerlad

<sup>1</sup>East Suffolk North Essex Foundation Trust, Colchester,

Background: Cleft surgery, a small and highly-specialised subspecialty, poses a complex and competitive training pathway.

Aims: This research will identify and comprehend barriers to cleft surgical training, while exploring strategies to overcome these barriers.

Methods: 10 post-CCT cleft surgeons who trained in the UK underwent semi-structured interviews, exploring cleft training's unique attributes, barriers, the Training Interface Group (TIG) fellowship and strategies in overcoming barriers. 7 of the 10 surgeons were currently practicing and 3 were retired.

Thematic analysis of anonymised transcripts was conducted to reveal themes to each question.

Results:

Cleft surgeons described the speciality as highly specialised, revolving around multidisciplinary team care from antenatal to adulthood with demanding technical expertise and complex decision-making. Surgeon seniority significantly impacts operative outcomes, alongside often anxious parents, resulting in procedures being taught at later stages of training.

Five barriers to training emerged: the specialty's perceived competitiveness dissuading potential trainees from considering cleft in the first instance (50%), challenges relocating to cleft centres due to vital fellowships occurring during childbearing years (60%), commitment to the speciality is needed before being able to operate independently (50%), lack of a guarantee of a substantive consultant post (50%) and potential relocation should one become available (50%). While the TIG fellowship was lauded as gold standard for its supernumerary status (80%) and tailored curriculum, its non-proleptic nature and timing during childbearing years were potential challenges. Once in a substantive post, cleft surgery proved to be family-friendly due to its large elective burden, minimal emergencies and could suit LTFT consultants (40%).

A proposed solution: ensure guaranteed substantive posts after fellowship (50%). This is crucial considering trainee deskilling and being unable to transition to a different subspecialty.

Conclusion: This study highlights potential challenges in cleft surgical training. A solution of guaranteed substantive posts post-fellowship was suggested, but requires further discussion.



## **CleftED: A National Collaborative Study of Undergraduate Education and Exposure to Cleft within the UK**

**Theodore Pezas**<sup>1</sup>, Umar Rehman<sup>2</sup>, Norma Timoney<sup>1</sup>, Duncan Atherton<sup>1,3</sup>

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Introduction: Cleft Lip and/or Palate (CLP) are the most common congenital orofacial anomalies. Those involved in CLP care may extend beyond the core members of the Cleft multidisciplinary team (MDT) with a variety of medical healthcare professionals destined to contribute to the management of CLP patients at some point during their respective careers. Therefore, it seems essential that a basic understanding of CLP, CLP-associated problems, and potential avenues for direct or indirect involvement in CLP care be introduced at undergraduate level.

Aims: To investigate penultimate and final year undergraduate medical student CLP knowledge and exposure obtained whilst at medical school.

Methodology: An online questionnaire was distributed to penultimate and final year medical students throughout the UK.

Results: A total of 3102 responses were received from 35 medical schools. 44.3% (n = 1374) of respondents had no exposure to CLP teaching up until their current year of education. 61.3% (n = 1903) of respondents had never been involved in the care of a CLP patient. 53.6% (n = 1662) of respondents were not confident in their current knowledge of CLP. 78.5% (n = 2257) of respondents indicated a desire to be involved in the care of CLP patients in their future career.

Conclusion: More than half of the medical student survey respondents were not confident in their current knowledge of CLP and had limited involvement in CLP care. This may translate to a delay in diagnosis when students qualify. Improving CLP education and exposure during undergraduate training can help achieve national CLP standards for early diagnosis.



### **A Nationalised Technical 3D Photography Protocol for Cleft**

**Dr Will Raby-Smith**<sup>1</sup>, Ambika Chadha<sup>1</sup>, Kanwalraj Moar<sup>1</sup>, Abbey Hespini<sup>1</sup>, Joe Matthews<sup>1</sup>, Johnny Volcano<sup>2</sup>, Julia Kepinska<sup>3</sup>, Piet Haers

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Background: A recent survey has demonstrated that, as a technology, 3D photography has reached the tipping point of adoption in UK cleft services<sup>1</sup>. The survey has highlighted the appetite for a national protocol akin to the 2D photography guidelines published in 2004<sup>2</sup>. Over the last 5 years, multiple stakeholders have been involved in finalising this protocol which is essential not only as a guidance document for photographers but also for the quality assurance and standardisation of 3D photographs. The latter is essential for meaningful analysis to generate cleft-specific Quantitative Image Biomarkers (QIB).

Aims & Objectives: The protocol aims to demonstrate the fundamental aspects of 3D photography that distinguish it from 2D photography. It details the process for image standardisation at the point of capture and beyond for subsequent analysis, either qualitatively or quantitatively. It also details a standardised approach to quality assurance of images taken by 3D photography.

Methods: The protocol was developed through a multiple stakeholder consensus opinion involving cleft clinicians, medical photographers, researchers and other relevant professionals. It is currently in the process of being ratified by the Institute of Medical Illustrators (IMI).

Results & Conclusions: The finalised protocol is a comprehensive technical guide to the use of 3D photography in cleft care, providing an important approach to the standardisation of 3D photographs. With an increase in the uptake of 3D photography across cleft services in the UK, this standardisation will become critical to the generation of large-scale 3D photographic data to permit further analysis of such patients. It is hoped that this approach can contribute to a deeper understanding of cleft morphology and surgical outcomes.

References:

1. Gladwell M. The Tipping Point: How Little Things Can Make a Big Difference, 2013
2. Institute of Medical Illustrators. Photography of cleft audit patients, 2004



## Cleft dental deserts - the difficulties accessing primary dental care

**Dr Georgia Hallett**<sup>1</sup>, Dr Constance Hardwick<sup>1</sup>, Dr Amy Hollis<sup>1</sup>, Dr Victoria Clark<sup>2</sup>, Dr Mechelle Collard<sup>3</sup>, Dr Olusegun Olujide<sup>3</sup>, Dr Joanna May<sup>4</sup>, Dr Jeanette Mooney<sup>5</sup>, Dr Mary Busseell<sup>6</sup>, Dr Giles Kidner<sup>6</sup>, Dr Nabina Bhujel<sup>7</sup>, Dr Mina Vaidyanathan<sup>7</sup>, Dr Julie Mitchell<sup>8</sup>, Dr Jancy Pope<sup>9</sup>, Dr Helen Saunders<sup>10</sup>

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Background: Access to primary dental care is a widely known issue for many families. Children born with cleft lip and or palate (CL+/-P) are at higher risk of dental caries and anomalies and therefore regular dental attendance is important 1. Delivering Better Oral Health Toolkit recommends 3-6 monthly dental attendance with appropriate preventative care and support in the primary dental care setting<sup>2</sup>.

Aim: To evaluate access to primary dental care for children born with CL+/-P

Objectives:

For children born with CL+/-P:

Evaluate ease of access to dental care

Describe distances travelled to access primary dental care

Evaluate dental attendance intervals

Evaluate application of fluoride varnish

Methods: Questionnaires were distributed at multidisciplinary clinics at eight UK cleft centres. Data was collected via questionnaire completion from parents/carers of children born with CL+/-P.

Results: 547 completed questionnaires were analysed. Nearly one third (n=128) of respondents reported difficulty accessing dental care with 6% travelling over 10 miles (n=33). Correct dental recalls of 3-6 months were met in 56% of respondents (n=302).

Only 39% (n=213) reported fluoride varnish application despite a majority reporting they had a dental home.

Conclusions: Parents/carers of children born with CL+/-P are struggling to access primary dental care. Those who are accessing care are not always seen at appropriate recall intervals or given the correct preventative care. Children born with CL+/-P who are not seen regularly may present with more advanced dental disease requiring intervention, potentially delaying cleft surgical procedures. This is the first national data collection and analysis of primary dental care access for children born with CL+/-P.

References

1. May, J., Smallridge, J., Collard, M. et al. (2023).
2. Department of Health. Delivering better oral health: an evidence-based toolkit for prevention (2021)

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## Development and growth of nasal obturator provision at the South West Cleft service.

**Joanna Waldron**<sup>1</sup>, Anne Roberts<sup>1</sup>, Alistair Cobb<sup>1</sup>, Amy Davey<sup>1,2</sup>, Scott Deacon<sup>1</sup>, Josie Steel<sup>1</sup>

<sup>1</sup>South West Cleft service, Bristol, UK, <sup>2</sup>North Bristol NHS Trust, Bristol, UK

Background: The South West Cleft service experienced unprecedented delays to Velopharyngeal Insufficiency (VPI) surgery following the COVID-19 pandemic. Persisting VPI is associated with poorer speech and psychosocial outcomes.

Aims: To develop a service for bespoke nasal obturators (NUGs) for patients with VPI waiting for speech surgery.

Method: An application for a new intervention procedure was approved by Trust Clinical Effectiveness and subsequently a pilot NUG clinic was completed with 17 patients (3;11 – 42 years). Results were collected and presented internally showing a need for the continuation of a nasal prosthesis service as either a short or long term solution for VPI. A Standard Operating Procedure, patient information leaflet and referral criteria were developed. Design modifications were made to improve functionality and aesthetics of NUGs and feedback was gathered from Speech and Language Therapists using NUGs in therapy. Growth of the service lead to a new stakeholder being recruited, the innovation of a same day impression and fit clinic, external referrals, and funding

for additional speech and language therapy time. Fitting training for regional cleft speech and language therapists and involvement from cleft psychology has also helped to expand the service.

Conclusion: The NUG service offers both an interim and long term solution to address VPI. NUGs facilitate and expedite progress in speech therapy. The service has helped to mitigate against longer waiting times for speech surgery. Future aims include patient reported outcomes and further assessing long term use.



# Free Paper Session 5 - Psychology & Data

## What do young people with cleft lip with/without palate think about their appearance?

**Julie Davies**<sup>1</sup>, Dr Amy Burton<sup>2</sup>

<sup>1</sup>NWNW & IoM Cleft Network, Manchester, UK, <sup>2</sup>Staffordshire University, Stoke-on-Trent, UK

Young people with a cleft lip with or without palate (CL+/-P) have expressed their concerns about their appearance and the sharing of their image on social media. Using exploratory qualitative methodology this study aimed to explore and understand young people's views and experiences. Thirteen young people, aged 16-20 years (mean age = 17.8 years), ten females and three males with a CL+/-P (two with cleft lip only (CL), nine with a unilateral cleft lip and palate (UCLP) and two with a bilateral cleft lip and palate (BCLP)) participated in virtual, semi-structured interviews. Photo-elicitation was used to facilitate the discussion. The young people were asked to provide three photographs of themselves that they liked and three that they did not like. Recordings from the interviews were transcribed verbatim and analysed using Reflexive Thematic Analysis. Four themes were developed: (1) Symmetry equals beauty, (2) Controlling and curating a positive self-image, (3) Acceptance with maturity and (4) Connections can promote empowerment. These themes highlight the concerns that the young people have with their appearance, how they present their self-image to others and how they have become empowered to embrace their cleft and support others.



## A Decade of Data: Exploring Cleft Trends in Psychology Referrals compared to National Birth Prevalence.

**Dr Aimee Pudduck**<sup>1</sup>, Dr Tom Henwood<sup>1</sup>, Erin Morgan<sup>1</sup>, Jade Evans<sup>1</sup>

<sup>1</sup>Welsh Centre for Cleft Lip and Palate, Swansea, Wales

Background: At annual review of Psychology referral data at the Welsh Centre for Cleft Lip and Palate, there appeared to be many more referrals for UCLP to Psychology than the National Prevalence of births, and much less referrals to psychology for CP only. The psychology team decided to review referral data for the last decade to look at Psychology referrals by Cleft Type.

Method: Data from 2012-2022 was screened using excel and SPSS. The data explored the number of referrals to Psychology by Cleft Type (UCLP, BCLP, CL, CP), type of referral and gender. Percentage of Cleft type data was compared to the CRANE National Report data to allow comparisons with average Cleft type prevalence data for the same 10 year period.

Results: Over a 10 year period, there were 594 referrals to Psychology, 487 of which were from individuals with UCLP, BCLP, CL, CP. It was found that the psychological need across cleft type was not linear, as there were greater needs for certain cleft types (BCLP (16.7%), UCLP (37.9%), CL (13.7%), CP (31.7%)) when compared to the national prevalence of births (BCLP (9.6%), UCLP (21.4%), CL (24.1%), CP (43.31%)), with statistically significant differences found. Data was also obtained for type of referral, age and gender, and this will be presented.

Conclusion: In noticing these data trends, hypotheses were explored as to why Psychology Referrals might differ by Cleft Type, and to consider further exploration of the psychological needs of those with different Cleft Types. This would inform our service offerings to ensure that we are fully supporting the needs of our families. Discovering if this is a wider trend across cleft services in the UK might also allow for the development of targeted psychological interventions/preventative measures by Cleft Type.



## Psychological Impact of Lip Filler in Cleft Lip Patients

**Araminta Corbett**<sup>1,2</sup>, Dr Aimee Pudduck<sup>1</sup>, Dr Tom Henwood<sup>1</sup>, Tomos O'Neill<sup>1</sup>

<sup>1</sup>Welsh Centre for Cleft Lip and Palate, Swansea, Wales, <sup>2</sup>Cardiff University, Cardiff, Wales

Background: Cleft patients often have appearance-related concerns impacting on self-image, self-confidence, and quality of life with related impact on mental health. The Welsh Centre for Cleft Lip and Palate offers a lip filler clinic as part of cleft care. The evidence base indicates the use of filler is aesthetically effective and patients report satisfaction (Rivers et al. 2023, Thompson et al. 2023), however there is no published evidence of the potential positive or negative psychological impact of this.

Method: Pre and post treatment CLEFT-Q Lip Module data collected from 28 patients who received lip filler as adults after a historical lip repair will be analysed and supplemented with survey data to enrich the understanding of the psychological impact in this population. Stakeholders including a consultant cleft surgeon, nurses and a consultant orthodontist, will also be interviewed to collect qualitative data on offering this intervention in a Cleft Service. This data will enable us to evaluate and experiences of both patients and stakeholders and give richer understanding of the psychological impact of the intervention.

Results: Initial analysis indicates patient satisfaction from pre and post treatment scores, however the addition of qualitative data and stakeholder service related data will allow for deeper understanding of the underlying mechanisms and psychological impact of offering lip filler as a routine intervention in cleft care.

Conclusion: The results of this evaluation will allow us to better understand the psychological impact of offering this service routinely in a Cleft service. It will also illuminate the views of stakeholders on offering this service routinely and enable us to consider how this may inform future practice and service development.

References: Rivers et al. 2023, Thompson et al. 2023



## Psychological Outcomes by 20 Years Old

**Amy Warren**<sup>1</sup>, Dr Joanna Shearer<sup>1</sup>

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Background: Previous research has shown there to be a higher risk of psychological distress in adolescents than pre-adolescents with a CL/P[1].

Aims & Objectives: To explore patients' feelings in relation to their CL/P at the point of discharge from paediatric services.

Methods: Cross-sectional study (N=55) of routine 20 Year audit psychology reviews from April 2021-December 2023. Diagnoses included CP (N=24), CL (N=12), CLP (N=19). Cleft Hearing Appearance and Speech Questionnaire (CHAS-Q), Satisfaction with Appearance (SwA) and Hospital Anxiety and Depression Scale (HADS) were used as standardised measures.

Those who did not complete all 3 measures were excluded. 1 was excluded due to being aged 23 at time of review.

Results/Conclusions: Previous experiences of bullying/teasing were reported in 41.67% of CP, 83.33% of CL and 63.16% of CLP. Those who explained further reported name calling and comments on their nose, scar and speech, with this mostly occurring in primary and early secondary school. Only 1 patient (CL) reported this was still a problem, indicating minimal rates of bullying by age 20.

CP reported highest satisfaction with facial appearance out of 10 (M=8.2), and CL lowest (M=6.4). CP were the least satisfied with their speech (M=7.2) whilst nose satisfaction was lowest in CL (M=6.25) and CLP (M=6.2). Those with only CL appeared the least satisfied with their appearance by age 20.

Approximately 20% of anxiety scores and 0% of depression scores were within the abnormal range for CP. For CL, this was 25% (anxiety) and 8% (depression). For CLP, 32% (anxiety) and 0% (depression). This data indicated lower levels of depression across all cleft types compared to the general population (22%[2]). Anxiety in CLP was higher than the general population (28% [2]), although CP and CL were again lower.

References:

1. Kelly & Shearer (2020)
2. Office for National Statistics (2021)





## Lives of Irish Adolescents who were Born with a Cleft

### **Catherine de Blacam**<sup>1</sup>

<sup>1</sup>Children's Health Ireland, Dublin, Ireland

Background: As patient-reported outcome measures such as the Cleft-Q have been validated in individuals who were born with a cleft, they do not allow us to report how our patients compare to their peers in the general population in terms of psychological wellbeing.

Aims & Objectives: To describe the lives of 13-year-old children who were born with a cleft in comparison to the general population as recorded in Growing up in Ireland (GUI), the national longitudinal study of children and youth in Ireland.

Methods: GUI questionnaires were adapted in conjunction with PPI contributors and administered to adolescents registered on the Dublin Cleft Centre database, who were born between 2007-2009. Data were registered in a REDCap database and compared to that of the GUI cohort '08.

Results/Conclusions: Twenty-nine adolescents (9 female, 21 male) participated. The majority of participants had settled well in to secondary school and reported an expected educational attainment of a higher degree (72%, versus 69% of GUI participants). The average Mental Health Inventory (MHI-5) score was 75.4 out of 100, versus 80.0 in the GUI cohort. Self-esteem was recorded using a modified Rosenberg scale, with the LIA-Cleft group scoring 11.9/18 versus 13/18 in the GUI group. When asked to rate overall satisfaction with life on a 1-10 scale, 54% of the LIA-Cleft group recorded a score >8, versus 72% of the GUI group.

Though the LIA-Cleft sample was small and heterogenous, there were some notable differences between their socio-emotional and wellbeing scores and those of the general population. This information will help to inform service development, particularly in relation to targeting psychological support for patients of the cleft service. The study also serves as a proof of concept for use of GUI questionnaires in studies comparing children born with congenital conditions to peers in the general population.



## **Cleft Registry and Audit NEtwork linkage with the Newborn Hearing Screening Programme.**

### **Sophie Butterworth**<sup>1</sup>, Kate Fitzsimons<sup>1</sup>, Sinéad Davis<sup>2</sup>, Victoria Parfect<sup>3</sup>, Jibby Medina<sup>1</sup>, Jan van der Meulen<sup>1</sup>, Craig Russell<sup>1</sup>

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Introduction: The Newborn Hearing Screening Programme (NHSP), commissioned by NHS England, is responsible for hearing loss detection among English newborns(1, 2). Early detection of hearing loss and timely intervention can improve acquisition of speech and language skills. For the first time we have been able to link the Cleft Registry and Audit NEtwork (CRANE) to the NHSP to explore the detection and aetiology of hearing loss in a population of children born with a cleft.

Aims:

1. To link consented children in the CRANE database to their individual NHSP record.
2. To determine the percentage of children who (a) undergo a newborn hearing screening assessment and (b) have no clear response in one or both ears during their screening assessment.

Method: English children born 01 March 2006 - 31 December 2021, with consent to data linkage in CRANE were linked to NHSP records at an individual level. Data linkage rate was compared according to cleft type, sex and syndromic status. Chi-squared tests were used to compare percentages between subgroups.

Results: 11,944 out of 12,566 children (95%) had a linked NHSP record. 98% of linked children had a complete newborn hearing screening assessment; 2% had incomplete assessments. Linkage rates ( $p < 0.001$ ) and the outcome of screening ( $p < 0.001$ ) both varied significantly by cleft type. of those with a complete NHSP assessment, 76% had a clear response bilaterally, 10% had no clear response unilaterally and 14% had no clear response bilaterally.

Conclusion: It has been possible to link a high proportion of children registered in CRANE to NHSP records. Cleft type was found to significantly influence both linkage rate and screening outcome. Further work is needed to

explore the reasons for this variation and whether children were appropriately targeted for follow-up post screening.

1. Digital NHS. Overview of newborn hearing screening programme. <https://www.nhs.uk/conditions/baby/newborn-screening/hearing-test/>
2. Gov.uk. Newborn hearing screening: programme overview. <https://www.gov.uk/guidance/newborn-hearing-screening-programme-overview2013>



## **Optimising recording of national registry and audit data for cleft services using electronic workflow**

**Robert Manton**<sup>1</sup>, John Li<sup>1</sup>, Kana Miyagi<sup>1</sup>

<sup>1</sup>Cleft.NET.East Regional Cleft Service, Cambridge University Hospitals NHS Foundation Trust, Cambridge, UK

Background/Introduction: The Cleft Registry and Audit Network (CRANE)(1) is designed to collect information about all children born with cleft lip and/or palate in the UK. All cleft units are mandated to supply relevant information which is analysed and reported upon. This resource has many purposes culminating in ensuring optimal care is provided for those patients with clefts in the UK.

In the 2022 CRANE annual report 62% of units were negative outliers for at least one data component including the Cleft.Net.East service at Addenbrooke's Hospital in Cambridge.

Aims & Objectives: To create a streamlined, electronic workflow to optimise recording of patient data, with the following key pre-requisites:

1. Structured data recording to aid reporting and analysis
2. No additional workload to users
3. Integrates with current electronic records system (EPIC, Wisconsin, USA)

The key objective was to ensure that a high level of data completeness for CRANE submissions, to enable accurate benchmarking and prospective quality improvement.

Methods: Data points from the CRANE data dictionary were mapped to appropriate members of the multidisciplinary team along with the expected timeline of a patient assessed and managed in our unit. This process map informed the design of smart-forms to ensure data were recorded in a structured manner that provided the greatest flexibility for future retrieval and analysis.

Results/Conclusions: In creating specific forms for use by cleft services we have reduced data omissions, improved the quality of our data by standardising documentation processes and reduced workload for both clinicians and data managers. Our data can now be queried in a simple and efficient manner by any member of the MDT. Not only does this facilitate submission of accurate and complete data to CRANE, but it also improves our ability to conduct internal audit and research for the benefit of our patients.

References: CRANE Database(<https://www.crane-database.org.uk/>)



## **Post-centralisation Hospital Care for Children with Clefts in England: An Analysis of Hospital Episode Statistics**

**Dr Kate Fitzsimons**<sup>1</sup>, Dr Simon Barr<sup>2</sup>, Jibby Medina<sup>1</sup>, Sophie Butterworth<sup>1</sup>, Craig Russell<sup>1</sup>, Prof Jan van der Meulen<sup>3</sup>

<sup>1</sup>Clinical Effectiveness Unit, Royal College of Surgeons, London, UK, <sup>2</sup>Manchester University NHS Foundation Trust, Manchester, UK, <sup>3</sup>Department of Health Services Research and Policy, London School of Hygiene and Tropical Medicine, London, UK

Background: Cleft services in England were centralised between 1997 and 2007. During this time, a national study showed that children with isolated clefts had an average of 3.2 admissions and 13.2 days in hospital in the first two years of life. The impact of centralisation on hospital care has not yet been reported.

Aims: To analyse hospital admissions within two years of birth among children with cleft lip and/or palate.

Methods: NHS Hospital Episode Statistics were analysed for children born 2008-2017 who received a primary cleft repair before their second birthday. Number of admissions and total days in hospital were calculated and analysed according to absence/presence of additional congenital anomalies and cleft type.

Results: 9,057 children were included. Children without additional anomalies (n=6,576) had on average 3.4 admissions and 10.9 days in hospital. Children with additional anomalies (n=2,481) had 6.9 admissions and 45.1 days in hospital. Cleft-related admissions and total length of stay decreased significantly over the 10-year birth period (p<0.001) and 10-year means were similar in children without (1.6 admissions, 4.1 days) and in those with additional anomalies (1.5 admissions, 6.4 days). Among children with a cleft alone, 38.0% had ≥1 emergency admission and 4.4% had ≥1 emergency readmission within 14 days of primary repair. Day-case surgeries represented 6.9% of primary lip repairs, 0.7% of palate repairs and 1.0% of lip+palate repairs. The mean length of stay was 2.7 days for primary lip repair and 2.9 days for primary palate±lip repair. Number of admissions and time in hospital increased with increasing anatomical involvement of the cleft (p<0.001).

Conclusions: This study demonstrates that children now spend less cleft-related time in hospital since cleft services were centralised. The findings will inform the commissioning and structure of cleft services and will be useful for new parents of children with a cleft.



## **Temporal and Geographical Epidemiology of Cleft Lip and Palate in South Wales**

**Thomas Jovic**<sup>1,2</sup>, Helen Extence<sup>1</sup>, Tomas O'Neill<sup>1</sup>, CRANE Database

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Introduction: The incidence of cleft has been previously cited as between 14.7 to 20.3 per 10,000 live births in Wales. This study aimed to quantify the incidence of isolated cleft lip, cleft palate, unilateral and bilateral cleft lip and palate in Wales, and highlight geographical areas of greatest incidence.

Methods: An 8-year study period was used (2013-2021) to determine temporal and geographical incidence of cleft in South Wales. The CRANE database was used to identify patients born in South Wales with a diagnosis of cleft lip and/or palate and Pierre Robin sequence. Geographic data was attained to map regions of greatest incidence. The Office of National Statistics database on live births was used to calculate incidence per 10,000 live births.

Results: A peak incidence of 17.9 clefts per 10,000 live births in 2018 and a trough of 10.4 per 10,000 live births in 2016, with a mean incidence of 14.9 per 10,000 live births over the study period (1 in 688 live births). Whilst the highest number of cleft births (mean 14.3 cases per year) were in mid-South Wales, the incidence was highest in Southeast Wales (14.7 cases per 10,000 live births). Isolated cleft palate was the most common cleft with a mean annual incidence of 6.7 per 10,000 live births, whereas BCLP was the least common with an incidence of 1.6 per 10,000 live births. PRS had an incidence of 2.2 per 10,000 live births.

Discussion: This epidemiological study highlights both temporal and geographic variation in cleft incidence in Southern Wales, with a mean incidence of 14.9 per 10,000 live births. Our incidence of PRS is almost double the globally cited incidence and we demonstrate a persistently higher incidence of cleft in Southeast Wales relative to other geographical areas. These findings present implications for service delivery and risk identification.



## **Cleft case ascertainment in the CRANE Database compared with Hospital Episode Statistics data in England**

**Dr Kate Fitzsimons**<sup>1</sup>, Dr Sophie Butterworth<sup>1</sup>, Jibby Medina<sup>1</sup>, Prof Jan van der Meulen<sup>2</sup>, Craig Russell<sup>1</sup>

<sup>1</sup>CRANE Database, Royal College of Surgeons, London, UK, <sup>2</sup>Department of Health Services Research and Policy, London School of Hygiene and Tropical Medicine, London, UK

Background: The CRANE Database is a national registry of all live births affected by a cleft in the UK. The Hospital Episode Statistics (HES) database contains records on all diagnoses and treatments provided during individual admissions to NHS hospitals in England.

Aims and objectives:

1. Compare the number of English CRANE registrations with the number of cleft cases identified in Hospital Episode Statistics;

2. Estimate the prevalence of live births affected by a cleft using CRANE and HES data sources and the national live birth rate in England.

Methods: CRANE cases, born 01/01/2009-31/12/2018, registered by English Cleft Services were included to match NHS Trusts covered by HES. Patients in HES, born 01/01/2009-31/12/2018, were included if they had 1) an International classification of Diseases (ICD-10) code for cleft lip and/or palate (Q35/Q36/Q37) and 2) a Classification of Surgical Operations and Procedures (OPCS-4) code for primary cleft repair (F031/F291), or a death record occurring before a repair would be performed, according to UK guidelines. HES records up to 30/03/2020 were reviewed. Children with a 'Foreign' region of residence were excluded. The number of live births in England was obtained from the Office for National Statistics and used to estimate the prevalence of live cleft births as a percentage of all live births.

Results: 10,090 children were included from CRANE and 10,033 from HES. Based on 6,666,440 live births, the 10-year average prevalence rate per 10,000 live births was 15.1 for both datasets (1:661 live births based on CRANE; 1:664 live births based on HES), with annual rates ranging 14.1-16.2 using CRANE and 13.8-15.9 using HES.

Conclusions: This study indicates high case-ascertainment levels in CRANE and suggests registrations are representative of the true prevalence of clefting among live births in England, particularly among those that require cleft treatment.



# Poster Presentations

(Alphabetical by Presenting Author Surname)

## Speech Outcomes in Cleft Palate Patients: The Impact of Syndromes and Comorbidities

Hadyn Kankam<sup>1</sup>, **Shweta Aggarwal**<sup>1</sup>, Louise Cafferky<sup>1</sup>, Holly Peryer<sup>1</sup>, Imogen Underwood<sup>1</sup>, Dr Hannah John<sup>1</sup>  
<sup>1</sup>West Midlands Cleft Service, Birmingham Childrens Hospital, Birmingham, UK

Background: Speech outcomes in children with cleft palate with or without cleft lip (CP/L) are often expected to be worse in children with syndromes or other comorbidities (CP/L+) compared to those without (CP/L-). This study investigates the five-year speech outcomes of a one-year CP/L birth cohort, managed at a UK regional cleft centre.

Aims: To compare speech outcomes between CP/L+ and CP/L- patients  
To compare the rate of revision palate surgery between CP/L+ and CP/L- patients

Methods: A retrospective chart review of all CP/L children referred to a regional cleft centre in 2012 was performed. The cleft audit protocol for speech (CAPS-A) tool was used to assess speech at five years of age. Comparisons between CP/L+ and CP/L- groups were performed.

Results: Over the study period, 114 CP/L patients were referred to our service, of which 46 were identified as having additional comorbidities/syndromes (CP/L+). Speech assessments using the CAPS-A tool were performed for 68 patients. Of this cohort, 81% of patients had a good five-year speech outcome of resonance and nasal airflow characteristics (RNA) with no evidence of a structurally related speech problem and 57% had no cleft speech characteristics (CSCs) requiring therapy or surgery. No significant differences in the RNA ( $p=0.16$ ) or CSCs ( $p=0.50$ ) results were observed between the CP/L+ and CP/L- groups. Revision palate surgery was required in 16% of patients, with no significant difference between CP/L+ and CP/L- patients ( $p=0.42$ ). Some patients could not be assessed using the CAPS-A tool due to the complexity of their co-morbidities.

Conclusion: Comorbidities often delay treatment and add to the burden of care of patients requiring cleft palate surgery. However, this study indicates that despite such delays, speech outcomes and the incidence of revision surgery were similar in CP/L+ and CP/L- patients.



## Platelet-Rich Fibrin in Secondary Alveolar Cleft Bone Grafting: An Update to The Current Literature

**Dr Mohammad Abdelhamid Moheyeldin Ahmed**<sup>1</sup>

<sup>1</sup>Faculty of Oral and Dental Medicine - Delta University, Mansoura, Egypt

Introduction: Alveolar cleft (AC), which was present in 75% of cleft lip and palate (CLP) patients, was considered the most congenital bone defect in human beings [1]. Secondary alveolar cleft bone grafting (SABG) was reported as the most acceptable approach for AC repair. Platelet-rich fibrin (PRF) was substantially considered in improving bone and soft tissues healing in the maxillofacial spectrum [2].

Purpose: To investigate clinical and radiographic outcomes of PRF in SABG.

Patients and Methods: Twelve patients with unilateral ACs were involved in a randomized controlled clinical trial that targeted SABG from the chin. Six patients received SABG without PRF (Control group), and six patients received SABG with PRF as a membrane and within the bone grafts (Study group). The outcome variables were recurrence of oronasal fistula, volume and relative density of newly formed bone within the cleft area. Statistical data were analyzed, and the statistical significance was stated when  $p < 0.05$ .

Results: The difference between the two groups was not statistically significant in terms of oronasal fistula recurrence and volume of newly formed bone;  $p = 0.699$  and  $p = 0.283$ , respectively. However, the difference between both groups regarding relative density of the newly formed bone was statistically significant;  $p = 0.002$ .

Conclusion: PRF involved in SABG was shown to improve closure of the oronasal fistula and bone volume of the newly formed bone clinically and radiographically, but not to a statistically significant level. It succeeded, on the other side, to improve the relative bone density to a statistically significant degree.

References:

1. Mundra LS, Lowe KM, Khechoyan DY. Alveolar bone graft timing in patients with cleft lip and palate. J Craniofac Surg 2022;33(1):206–210

2. Shawky H, Seifeldin SA. Does platelet-rich fibrin enhance bone quality and quantity of alveolar cleft reconstruction? *Cleft Palate Craniofac J.* 2016;53(5):597-606

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### **Primary molars with enamel defects in cleft lip and/or palate patients: a multicentre evaluation**

**Teslimat Ajeigbe**<sup>1</sup>, Jeanette Mooney<sup>2</sup>, Mechelle Collard<sup>3</sup>, Nabina Bhujel<sup>4</sup>, Mina Vaidyanathan<sup>4</sup>, Jacqueline Smallridge<sup>5</sup>, Joanna May<sup>6</sup>

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Introduction: Cleft lip and/or palate (CLP) is associated with several dental anomalies, including enamel defects such as hypoplasia or hypomineralisation. The majority of the literature on enamel defects in this cohort is centred around primary incisors and permanent incisors/molars - there is little research on enamel defects in primary molars. Here we report the results of a multicentre evaluation on enamel defects in the primary molars of CLP patients in England and Wales.

Aims: To establish the prevalence of enamel defects in the primary molars of patients with CLP in England and Wales, find possible associations and determine the dental management of these teeth.

Methods: The dmft (decayed, missing or filled teeth) audit records of 5-year-olds born in 2012/2013 that attended the cleft units in Liverpool (n=104), Manchester (n=128), South Wales (Cardiff, n=97), London (Evelina, n=82) and Cambridge (n= 68, 2012 only) were reviewed. Patients with at least one primary molar with an enamel defect were included. The clinical notes, photographs and radiographs of included patients were then examined.

Results: Of the 461 CLP patients with 5-year-old audit data available, 12% (n=54) had evidence of enamel defects in at least one primary molar. Cleft palate (41%) and unilateral cleft lip and palate (35%) were the most common cleft types associated with enamel defects in primary molars. 13% of cases (n=7) were associated with cardiac co-morbidities and 13% of cases were syndromic (n=7). 23% of affected primary molars were also carious. The most common management for caries-free affected molars was prevention alone (55%) and the most common management for carious affected molars was composite restorations (31%).

Conclusions: There may be a higher prevalence of enamel defects in the primary molars of children with CLP. Conducting a national prospective audit may allow for further exploration of this hypothesis in the future.

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### **Cleft orthognathic surgery outcomes and complications; can we move towards day case operating?**

**Christopher Blore**<sup>1,2</sup>, Junaid Rashid<sup>1</sup>, Ian Sharp<sup>1,2</sup>

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Background: Orthognathic surgery often represents the final surgical intervention for cleft patients with residual dentofacial discrepancy. The complications associated with orthognathic surgery in the cleft population have been previously described<sup>1</sup>. In the non cleft population, it has been shown that day case orthognathic surgery is a viable option<sup>2</sup> but the cleft population has not previously been reported. With increasing pressure on beds in UK hospitals and a trend towards increased day case operating, can we now consider a day case approach?

Aims/Objectives: To assess the outcomes and complications for all cleft patients undergoing orthognathic surgery in a single UK cleft centre

To assess complications in a cohort undergoing cleft orthognathic surgery as a day case procedure and compare with the non-daycase cohort

Methods: Retrospective assessment of adult patients over 7 years from 2016-2022 in a single UK cleft centre, treated by a single Maxillofacial surgeon. Review of case notes, speech assessments, emergency attendances and correspondence documents for complications. Direct comparison between day case/ non-day case patients regarding complications and outcomes

Results/Conclusions: 45 patients treated of which 7 treated as day case. All day cases were single jaw movements. Overall degree of movements and complications not significantly different between daycase/ non daycase groups.

This case series suggests that day case cleft orthognathic surgery is viable with appropriate case selection but further work is needed with a larger cohort.

#### References:

1. Moran I, Virdee S, Sharp I, Sulh J. Postoperative complications following Lefort 1 maxillary advancement surgery in cleft palate patients *The Cleft Palate-Craniofacial Journal* 2017;55(2):231–7.
2. Bergmann U, Jónsdóttir OH, Bergmann JB, Björnsson GÁ. In-office outpatient orthognathic surgery: Review of 254 cases where the patients were discharged the same day. *International Journal of Oral and Maxillofacial Surgery*. 2023;52(7):801–5



### **Looking at ‘Psychological Function’ using Cleft Q in a pilot ‘Early Adult’ Clinic**

**Dr Katherine Berlouis**, Toby Gillgrass, Dr Rebecca Crawford<sup>1</sup>

<sup>1</sup>National Cleft Surgical Service for Scotland, NHS Scotland, Glasgow, Scotland

**Aims & Introduction:** There is limited long term outcome data for adults with cleft, with no specific UK data set agreed. However, there has been an increased focus on adult cleft care over the last few years (Ardouin, K. et al., 2020; Ardouin, K. et al., 2021) and enthusiasm to progress with this.

The National Cleft Surgical Service for Scotland wished to investigate the Cleft Q as a potential outcome measure at approximately 20 years of age.

**Method:** People who attended the ‘Early Adult’ Clinic completed the Cleft Q questionnaire.

In addition to completing Cleft Q, a brief clinical assessment regarding any cleft related treatments needs was carried out and a plan was put in place to address these if appropriate.

**Results:** Quantitative data regarding patient scores on the ‘Psychological Function’ scale on Cleft Q will be presented in detail.

33% of people invited attended the pilot clinic and completed the Cleft Q, with 67% feeling they did not wish to attend or not responding.

**Conclusions & Limitations:** Initial findings suggest that the majority of patients scored positively for ‘Psychological Function’ on Cleft-Q.

Applicability and clinical interpretation of the Cleft Q ‘Psychological Function’ scale will be discussed further.

Limitations include small participant numbers, the study cohort being self-selected and low clinic attendance rates.

The challenges of gathering representative outcome data for adults will also be discussed further.



### **Cleft MDT's consideration of psychosocial factors when supporting young people’s decision making for orthognathic surgery**

**Holly Clegg**<sup>1</sup>, Kiki Mastroyannopoulou<sup>2</sup>, Dr Eliane Young<sup>3</sup>

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<sup>3</sup>Psychological Medicine for Children, Young People and Families, Cambridge University Hospitals, Cambridge, UK

**Background:** Previous research has explored the decision-making experiences of young people and their parents with respect to surgery, however less is known about how clinicians experience this process, specifically when considering the transition period and supporting young people in their decision making for orthognathic surgery (‘OS’). “Psychosocial factors” refer to characteristics that influence an individual’s wellbeing either by impacting on them psychologically or socially. It is widely recognised that those affected by a CL/P may experience psychosocial difficulties, for example, experiencing difficulties with self-esteem or engaging in social situations however it is unknown how these experiences are considered by clinicians or what ethical dilemmas may arise during decision making.

**Aims/Objectives:** The purpose of this study was to explore what factors are considered by different MDT professionals working in CL/P services when supporting young people in making their decision around OS and to understand how different professionals consider and manage different ethical dilemmas that may arise during these interactions.

Methods: A qualitative design was employed, in which semi-structured interviews were conducted remotely with NHS staff. Nine participants from across four NHS cleft services were interviewed, of which the sample consisted of three Speech and Language Therapists, three Orthodontists and three Surgeons; all of whom are involved in the decision-making process for OS.

Results/Conclusions: Three major themes and seven sub-themes were identified through the process of conducting a thematic analysis. Themes included 'navigating the decision making process', 'Team Centric' and 'Health Inequalities impacting on access to cleft services'. Clinical implications arose with regards to how teams optimise the shared decision-making environment, foster opportunities for team liaison and consider health inequalities that impact on care. Future research may seek to explore health inequalities in greater depth.

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## **A group intervention for children with Cleft Palate/Non-Cleft VPI to generalise targeted speech sounds**

Catrina Dyer<sup>1</sup>, **Kathryn Da Costa Greaves**<sup>1</sup>

<sup>1</sup>Manchester Foundation Trust, Manchester, UK, <sup>2</sup>Alder Hey NHS Foundation Trust, Liverpool, UK

Introduction: It is well documented that generalising 'good' speech from the clinical setting to other situations is difficult for many children (Golding-Kushner, 2001). This may impact their literacy, socialisation, behaviour and school attainment (Law et al. 2003). It is advocated that group therapy may be more appropriate when the focus is on generalisation (Preston and Leece in Williams et al. 2020).

Purpose: To investigate whether a group intervention approach can improve the generalisation of targeted speech sounds for school-aged children with persistent speech sound disorder (SSD) secondary to cleft palate +/- lip or Non-Cleft VPI. The intervention also aimed to encourage participation with peers and inform parents/carers how best to support their child at home.

Method: Six participants (6-11 years) with long-standing SSD associated with cleft palate or Non-cleft VPI and their parent/carer attended a group intervention day. The participants were recruited from existing speech therapy caseloads from across the NWNW network. The intervention involved high-volume production of target speech sounds elicited through group activities. Formal speech assessments and Quality of Life questionnaires were undertaken to measure outcomes pre and post intervention.

Results: The generalisation of targeted speech sounds to spontaneous connected speech was observed post intervention in some of the participants. The feedback from participants and parents/carers was very positive and they reported benefits from attending the group intervention.

Conclusion: A group intervention approach outside of the clinical setting with peers can help to support generalisation of targeted speech sounds. Collaboration as a network has helped to establish a process to identify and treat children who may benefit from this intervention. This study lacked the use of a comparison and further analysis and research is needed.

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## **Comparative analysis of a dramatic change in protocol for patient attendance at CLPMDT clinics**

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Introduction: The COVID-19 pandemic has necessitated significant modifications in healthcare delivery. Particularly in specialised fields like cleft care, these changes have had profound implications on clinical interactions, patient outcomes, and healthcare efficiency.

Aims & Objectives: This evaluation aims to compare clinical interactions within a cleft clinic for one year before and after the onset of COVID-19. The objectives include assessing the nature and volume of these interactions, evaluating the impact on clinical outcomes and patient satisfaction, and understanding the implications for future healthcare delivery models.

Methods: The study employs a retrospective analysis approach, using data collected from electronic health records pre-COVID and post-COVID. The data encompasses types of appointments, patient demographics, clinical outcomes, and patient feedback. The analysis involves comparative statistics to identify trends and changes in clinical practice.



Results / Conclusions: Preliminary findings indicate a significant shift in the mode of clinical interactions post-COVID, with an increase in virtual consultations and a corresponding decrease in face-to-face appointments. Initial data suggests improved patient satisfaction and reduced travel times, potentially leading to better resource utilisation and patient adherence to treatment plans. The project's outcomes are expected to provide insights into optimising clinical practices in the post-pandemic era, enhancing patient care while maintaining efficiency.



## **Adult Returners to Cleft Care**

**Dr Elaine Davidson**<sup>1</sup>, Victoria Parfect  
<sup>1</sup>CUH - Cleft Net East, Cambridge, UK

Background: Adult re-entry to Cleft care has been identified as a priority by the Cleft Development Group. Currently there is no standard agreed pathway for transition or adult cleft care in the UK. It is therefore necessary to evaluate how Cleft teams manage individuals who return in adulthood.

Aim: To provide baseline data, initiate quality improvement and stimulate discussion at an Annual Tri-center meeting focused on adult returners, transition, and discharge in the UK Cleft Care Pathway.

Method: A Live, interactive, anonymous poll of Multi-disciplinary Cleft Specialty Clinicians was conducted at the start of the meeting (Cambridge, November 2023), focusing on current management, and clinicians experience of, adult returners, transition, and discharge. Rapid analysis of the results was presented at end of the day, and later more detailed analysis linked these with the presentations and themes raised.

Results: There were 39 (of 55) respondents. Responses included word clouds, free text and rating concepts. Results showed variation across units on management of adult returners. Adults return with multiple complex issues including mental health, appearance, changes in social circumstances and functional concerns. Main themes reflected the heterogeneity and complexity of adult returners, with the need for varying members of the MDT to be involved in their treatment plans. The importance of psychologists' role in triage, MDT appointments and treatment was a key theme throughout. Adult returners often have poor understanding of their previous cleft care. One outcome was around improving information communication and patients understanding around the time of transition and discharge.

Conclusion: Further evaluation of regional variation in the management of adult returners, transition process and discharge from the 0-20 Cleft Care pathway is indicated and could potentially result in further improving the cleft care delivered by UK Cleft Units.



## **A pilot study to explore reasons for the development of caries in 5-year-olds with CLP**

**Julie Davies**<sup>1</sup>, Dr Jeanette Mooney<sup>1</sup>, Dr Diana Graham<sup>1</sup>  
<sup>1</sup>NWNW & IoM Cleft Network, Manchester, UK

Background: Good oral health is paramount for children with a repaired cleft lip and/or palate (CLP) as care may be compromised by dental disease. In Manchester, audit data highlighted only 58% of 5-year-olds born in 2016 were dentally fit. Many studies examining the oral health status of children with CLP call for preventive programmes to be directed toward parents and their children. A pilot study to explore reasons for the development of caries in 5-year-olds with CLP will inform an intervention for use by the Clinical Nurse Specialist Team (CNS).

Aim: To improve knowledge and behaviour and reduce barriers to oral health care for our cleft families in Manchester.

Method: An examination of clinical notes recorded at multidisciplinary review clinics for children with CLP born in 2016 highlighted children with dental caries at 3 and 5 years. Using the CNS, National Nursing Standards of Care (Dental Health) 2010, questions were devised by Psychology and Dental colleagues. A guided telephone interview using the formulated questions will take place with a parent from each of the identified families. Data will be explored using thematic analysis.

Results: We plan to complete telephone interviews with 11 parents to identify themes of barriers to oral hygiene with their children with CLP. The 11 children identified were born in 2016 with CLP and have decayed, missing, filled score (dmft) ranging from 2 to 18 at age 3 years and 2 to 18 at 5 years in. Identified themes will be discussed.

Conclusion: Conclusions drawn from identified themes will formulate an oral health intervention underpinned by the National Nursing Standards of Care (Dental Health). This will be shared with our CNS Team and used with families in a timely manner. Longer-term assessment of both the intervention and oral health data will allow further conclusions to be drawn.



## **Morphological Changes in Craniofacial Microsomia**

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Craniofacial microsomia (CFM) is a complex congenital disease that affects the development of the craniofacial, extracraniofacial and dental structures. The latest statistics have noted that CFM affects one per 26,370 of the population. The causes of CFM have yet to be determined; however, experimental studies have suggested three mechanisms: the pathological consequences of the stapedia artery hematoma, developmental disruption of Meckel's cartilage and failure of migration of the neural crest cells. Although the literature describes many CFM cases with significant variations in the morphological alterations of the affected organs, there is less written about the scope of deformation that occurs in CFM. The aim of the review is therefore to explore the developmental anomalies in CFM cases and identify the types of malformations that occur. The study shows that mandibular hypoplasia is the predominant pathogenic sign of CFM. Ear malformations and weakness of facial and masticatory muscles are also highly reported. Further defects include ocular anomalies and facial nerve paralysis. The possibility of malformations in the extracranial structures is also high; the most common subtypes of deformations are scoliosis of the vertebral column, ventricular septal defect, renal agenesis and hydrocephaly. Furthermore, gastrointestinal and pulmonary malformations have been documented in a few cases of CFM. The incidence of dental anomalies involving the development and morphology of the teeth is slightly high.



## **3D scanning and Printing for Custom Nasal Obturation Production – A team approach.**

**Peter Llewelyn Evans**<sup>1</sup>, Steven Hollisey-McLean<sup>1</sup>, Lawrence Dovgalski<sup>1</sup>, Lisa Farquhar<sup>2</sup>, Helen Extence<sup>2</sup>

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In recent years the use of custom nasal obturation has become a viable treatment option for patients with velopharyngeal dysfunction. Through NHS Wales collaborations between the teams at the Maxillofacial Laboratory Department and Speech and Language Therapy Services we have developed a digital process which facilitates the fast, cost-effective production of a light, comfortable, unobtrusive custom nasal obturator and avoids the considerable time analogue custom treatments may take. We describe the technique from initial impression to fitting and outline the virtues and drawbacks of this method along with our audit and review protocols.



## **Exploring children's and young people's experiences of cleft lip and palate services: A Scoping Review**

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Background: The United Nations Convention on the Rights of the Child (1989) calls for inclusion of the child in healthcare decision-making. Despite this, there is limited academic research exploring the voice of a child/young person (YP) with a cleft lip and/or palate (CL+-P) in relation to services they receive (Jensen, 2022; Sharif et al. 2013). To evaluate what is already known, there is a need to review literature examining the healthcare experiences of a child/YP with CL+-P.

Aims/Objectives: To systematically scope literature reporting the views of children and YP with CL+-P and their parents and teachers regarding cleft related healthcare experience.

Methods: A Scoping Review (Peters, et al., 2020) was undertaken to identify publications on child/YP with CL+-P, their parent/carer or their teacher's experiences of healthcare for a child/YP. Databases searched in July 2023 included CHINAL, Web of Science, Pubmed, Cochrane, PsycInfo, Scopus, Speech Bite, Pro Quest, Google and

Google Scholar. Two reviewers independently reviewed: title and abstracts, 10% of full-text papers and the data extraction tool, developed based on JBI extraction tool (Peters, et al., 2020).

Results/Conclusions: From a possible 4255, 27 papers were included n= 14-qualitative, n=2-qualitative reviews of literature, n=7-mixed methods, n= 4-quantitative methods. Of these, n=21, focused on the parents and/or teachers of children with a CL+-P experiences of healthcare. Initial themes relate to access and barriers to healthcare, accessibility of resources, parental expectations and the involvement of child and their parents in treatment. Six studies examined the child's perspective of CL+-P's healthcare. Participants ranged between 5 and 20-years of age. Findings demonstrate a need to involve the child/YP directly in their care, to acknowledge the potential impact of living with CL+-P and to incorporate joint decision-making. This review highlights gaps in the evidence relating to experiences of CL+-P that should be explored to ensure the voice of the child/YP is included in decision-making.



## **Increasing Skills and Reducing Decay: Fluoride Varnish Training for Dental Care Professionals (DCPs) in Cleft**

**Sarah Fligelstone**<sup>1</sup>, Ruth Jones<sup>2</sup>, Mechelle Collard<sup>3</sup>

<sup>1</sup>Swansea Bay UHB, <sup>2</sup>Swansea Bay UHB, <sup>3</sup>Swansea Bay UHB/Cardiff University

Background: Dental caries is among the most prevalent non-communicable diseases. The risk is thought to be higher in children with a cleft lip and/or palate and in 2023, decay experience was 38% in 5-year-olds nationally, with 13% classified as extensive.<sup>1</sup> Treatment need within this population is already high, without this additional, largely preventable, burden. There is strong evidence supporting the application of fluoride varnish, a professionally delivered intervention, in the prevention of dental decay.<sup>2</sup>

Aims & Objectives: To ensure that all eligible cleft patients receive fluoride varnish applications by DCPs through bespoke in-house training. This initiative will also build the clinical skills of recipients.

Methods: Two dentists working with the cleft team are delivering the Making Prevention Work in Practice course. Each is supporting three individuals to gain competence in the provision of preventive advice and application of topical fluoride varnish. This will result in six DCPs with the necessary skills to deliver enhanced prevention on cleft clinics, currently none are able to provide this care.

Results/Conclusions: Data collection and feedback from the DCPs for the first Plan-Do-Study-Act cycle will take place between February and March 2024. Then, future action will be planned, including training more DCPs and adapting the training if necessary.

### References

1. Cleft Registry and Audit Network, 2023
2. Delivering Better Oral Health, 2021



## **Pregnancy Matters: NWNW Implementation of a Group Intervention for Carers Expecting Babies with Cleft Lip**

**Dr Diana Graham**<sup>1</sup>, Zoe Edwards<sup>2</sup>, Kate Moss<sup>1</sup>, Hannah Ridings<sup>1</sup>, India Brooke<sup>2</sup>, Leanne McDowell<sup>1</sup>, Paul Abeles<sup>1</sup>

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Background: Maternal mental health difficulties in pregnancy are often linked to an increased likelihood of psychological distress, premature birth, and reduced maternal-foetal attachment, which can ultimately impact the social, cognitive, and emotional development of the child (e.g. Norhayati, et al, 2015). Women carrying a baby with a prenatally diagnosed anomaly more commonly experience mental health difficulties during pregnancy and for up to a year following birth, compared to women experiencing healthy pregnancies (Asplin et al. 2015).

Aims and Objectives of Intervention: A 'Pregnancy Matters' group was developed by members of the cleft service in the Northwest, North Wales region as an early-intervention approach to support expecting parents who have received a positive prenatal screen for cleft lip.

This poster describes the delivery of Pregnancy Matters Groups over the last five years (2018 to 2023). The key focus of the group has been to explore the psychological impact of diagnosis, normalising this and fostering peer-

support. In later groups, an ‘expert by experience’ section was included, with a returning parent sharing their journey. Other topics were also offered, including 1) learning strategies to cope with feelings about diagnosis, 2) introducing carer-infant attachment and 3) information about child development. Opportunities were available to ask questions to one of the Cleft Nurse Specialists from the team, and information was given about accessing further Clinical Psychology input if required.

Methods/Evaluation: The evaluation of the groups via carer questionnaire feedback, together with some clinical routine outcome measures are also presented.

Conclusion: The achievements and challenges of running the groups, and the recommendations for future groups are discussed.



### **Implementation and evaluation of Patient Guides: Supporting patients and families through their peri-operative experience**

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Background: Within Spires, a need was identified to create readily accessible documents to not only provide children and families with practical peri-operative information but crucially, to facilitate psychological coping and resilience with the aim of reducing peri-operative anxiety, delays and cancellations to surgery and reduce the potential for traumatic reactions which may negatively impact future treatment pathways.

Aims & Objectives: To develop a series of guides to inform and support children and their families in the peri-operative period and to evaluate recipient’s views on these guides.

Methods: Several patient guides were developed with a suitable level of reading accessibility and included an interactive element to increase the engagement of a child audience. Guides were developed for some of the commonest procedures which would typically require direct input from the clinical team to manage peri-operative anxiety, e.g. alveolar bone graft, buccinator flap, pharyngoplasty and palate re/repair. The concept of the guides was to inform children above an age of comprehension rather than infants having their primary surgery. Each guide gave information on what to expect on the day of surgery and in the post-operative period. A visual pain scale was also included to facilitate communication of this important factor. Parents and children were asked for their views on the acceptability and utility of the guides via questionnaire method. Naturalistic sampling was used to determine the views of those that had received the guides in a clinical context.

Results/Conclusions: Questionnaire survey findings indicated that the guides were effective in reducing worry, facilitating preparation and were well-received by children and parents. Further areas for development include evaluating whether the guides were specifically effective in: helping parents in their conversations with their child, reducing service demands and enabling access to preparation for all, rather than only those who present in a specific way.



### **SLTs Perception of the Use of Ultrasound Imaging in Speech Therapy.**

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Background: There is growing evidence to support the use of ultrasound imaging as a tool for the assessment and treatment of speech disorders (Allen, 2023). The visual imaging of ultrasound can aid the identification of compensatory articulation (and, in particular, tongue positioning) and increase reliability of transcription. Transcription is typically used to categorise cleft speech characteristics in the identification of compensatory articulation in children born with cleft lip and palate (CLP) (Cleland, 2023). The Welsh Centre for CLP has introduced the use of ultrasound as part of the care pathway for patients.

Objective: The objective of this evaluation was to gain insight into SLTs perceptions of the use of ultrasound imaging in speech therapy.

Method: After 6 months use of an ultrasound at the Welsh Centre for CLP, a questionnaire was designed and distributed to record SLTs perceptions and usage of the ultrasound. The responses were analysed.

Results:

100% of SLTs responded. In summary:

- 67% of SLTs use the ultrasound at least once a month as part of the care-pathway for 11 patients aged 4 to 13 for informal assessment, eliciting sounds, and teaching tongue placement.
- The ultrasound has been used to mostly target alveolar plosives and velar plosives.
- Parents and children have been relaxed and motivated to use the ultrasound.
- Respondents agreed the ultrasound had benefits in assessment and therapy, being portable and providing a visual representation of speech sounds which aids SLTs and encourages patients to engage in therapy.
- Respondents identified it may be difficult for some patients to interpret what they are seeing, the ultrasound may be difficult for children with sensory needs, and there is an on-going cost for the gel.

Conclusion: The ultrasound has received a positive response and will continue to be used in the Welsh Centre for CLP.



**Inclusivity in Global Health Research Priority Setting: Can we do better? Lessons from CHNRI Cleft**

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Introductions/Aims: Inclusivity in research priority setting is fundamental to capturing the opinion of all stakeholders in a research area. This global research priority-setting exercise for orofacial clefts adapted the CHNRI methodology to include experts in the research field, but also clinicians from multiple disciplines and non-technical stakeholders (ie. patients and parents and NGOs) on a global basis.

Methods: Methodological changes were proposed and discussed by an expert steering group to improve inclusivity. These included survey edits, subgroups for research questions, a demographics section, translation in French and Spanish, phrasing adaptation and alternative dissemination techniques.

Results: There were 412 respondents and 1420 questions submitted. 78 different countries were reached (representing 40% of the countries in the world) and there were 18 different specialties/groups represented with surgeons being the highest participating group (30.4%) and patient/parent groups involving 8.96% of the collaborator population.

Conclusion: This is one of the first CHNRI exercises to involve patients and parents, along with clinicians and researchers in its first question submission stage. It is also the first-ever exercise to do so on a global scale. Challenges included translation errors, limited knowledge of response rates and receiving submitted statements rather than research questions. The adaptation of the CHNRI methodology allowed for a greater reach to various groups involved in cleft care to capture multiple viewpoints in the research prioritisation for OFCs.



**A Service Evaluation of the Royal London Dental Hospital Multidisciplinary Cleft Clinic Over a 12 Month Period**

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Background: The Royal London Dental Hospital (RLDH) is a tertiary referral centre for Adult cleft referrals requiring Orthodontics, Oral & Maxillofacial Surgery (OMFS) and Restorative dentistry. The multidisciplinary team (MDT) manages a range of cleft problems and works with the adult service in North Thames which contains, Speech and Language therapy, Plastic surgery, Clinical Psychology, ENT, Audiology and Orthodontics, based in Broomfield Hospital in Chelmsford.

Due to pressures on the NHS in primary dental care, in addition to the Hospital service, we aimed to assess the referral types and management outcomes for patients seen in a 12 month period.

Aims & Objectives: This project aims to evaluate the number of patients requiring OMFS, Restorative and Orthodontic care. Furthermore, this project will evaluate the need to refer patients back to primary care for routine dental work which they have not been provided.

This data will allow us to identify patient need and areas for optimisation to improve efficiency of the service, such as the need for a dental therapist.

Methods: The Trust database, CRS, was used to check the outcome of a sample size of 94 patient's Cleft clinic appointments from February 2022 to 2023 at the RLDH.

Results & Conclusion: Over 12 months, 208 appointments were booked, 179 were attended, meaning a 13.94% DNA rate, with an average of 15 patients per clinic. 61 new referrals were seen, overall there were 94 patients seen and managed.

In terms of service requirements by the three main specialities on the MDT, 45.74% (n=43) of patients required OMFS, 37.23% (n=35) required Restorative dentistry and 29.79% (n=28) required Orthodontics.

Patients requiring adult cleft care have complex needs and it is essential they are dentally fit prior to treatment. With the scarcity of NHS primary dental care this is challenging for them and the MDT service.



### **Use of virtual reality headsets to facilitate dental care for children with craniofacial conditions**

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Background: Children with cleft lip +/- palate (CLP) can often be more anxious regarding dental treatment<sup>1</sup> and have limited access especially in the anterior region. Traditional methods of providing care include inhalation sedation and general anaesthetic but these can compound the access issues, increase risks and waiting times for the child. Virtual reality (VR) headsets could be a potential solution to providing dental care under local anaesthetic for these children.

Aims: To evaluate the use of VR headsets to provide dental care for children with CLP.

Method: Two different VR headsets were available for a trial period at Royal Manchester Children's Hospital (RMCH) and Alder Hey Children's Hospital (AH). We recorded the patient demographics, VR experience used, treatments provided and any comments from operators and patients.

Results: 24 children used the VR headsets; 8 patients at RMCH, 16 at AH. The age ranged from 8-15 years and children had a range of different cleft and craniofacial conditions. Treatments provided included restorations, extractions and surgical exposures of canines. 23/24 patients (96%) completed treatment successfully. VR seems most effective for older children having one-off treatments such as extractions before alveolar bone grafts. Most patients found the VR a positive experience, parents liked it and operators found it easy to use.

Conclusions: The VR headset is an effective means of reducing anxiety without impeding access further. It is easy to use in any dental surgery but there are a few modifications which would improve its use for dental treatment further.

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## Early intervention in children born with a cleft palate (+/- lip)

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Introduction: At Alder Hey Children's hospital we offer a parent advice group for parents/carers of children born with a cleft palate (+/- lip) following primary surgery.

This poster aims to establish the effectiveness of our advice group.

Purpose: It is well documented that babies born with a cleft palate (+/- lip) are at a higher risk of developing speech difficulties (Hardin Jones et al, 2005) and dental caries (Grewcock et al, 2022).

In this group parents learn how speech and language skills develop and the impact a cleft palate can have on their child's speech development. Parents also learn about typical teeth development, oral health, and the impact a cleft can have on their child's teeth.

Cleft centres differ in how they provide speech and dental advice for children born with a cleft palate (+/- lip). We offer an interprofessional approach, delivered by a Speech and Language Therapist, a Dental Therapist and a CLAPA (Cleft Lip and Palate Association) representative. Interprofessional working in healthcare can benefit organisations, patients, and professionals (Wei,H et al, 2022).

Methods/results: We measured the feedback received with 13 pre and post parental questionnaires. The results indicate that all 13 parents felt their speech and dental concerns had been addressed and made some positive comments regarding their experience.

Conclusion: By continuing to measure how successful this intervention is we can plan and make changes that are necessary.

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## Patient Telephone Triage & Coordination of the Adult Cleft Clinic: A Service Evaluation

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Background: The Adult Cleft team at Alder Hey Hospital, Liverpool consists of Clinical Psychology, Oral and Maxillofacial Surgery, Orthodontics, Restorative Dentistry, Speech and Language Therapy. Adult cleft patients may have had varied exposure to MDT teams. Depending on their previous treatment, patients can therefore attend with a variety of individual concerns.

Patients reviewed on the Adult Cleft clinic may be already known to the team or new patients referred by another Healthcare provider. The current waiting time for a new patient attending this clinic is around 12-18 months. The Adult Cleft Service is overstretched due to increased referrals and staff shortages. This poses the question of how to efficiently staff the Adult Cleft clinic without impacting its effectiveness.

Aim: To investigate the value of telephone triage of new referrals to the Adult Cleft clinic.

Method: Prospective data collection through preliminary telephone triage of all new Adult Cleft clinic patients. Information collected by telephone triage was compared against the real outcome decided on clinic.

### Results:

Preliminary findings have highlighted that:

1. Patients are referred to the Cleft Service from a variety of sources and this has resulted in a lack of standardisation and/or negation of information required to triage the referrals effectively.

2. Initial referral data pertaining to the patient concern does not often correlate with the information given over the telephone.
3. Telephone triage has been received positively and, on occasion, has served as an appointment reminder or opportunity to modify appointment scheduling.

There are 11 clinics planned for 2024 with a current waiting list of 73 patients to be seen (24 new, 49 review). Data collected during this service evaluation will help to enhance the flow of adult cleft patients. It will also facilitate discussion around management of the Adult Cleft Service across the Network.

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## **Furlow Palatoplasty for Velopharyngeal dysfunction: Outcomes from a single centre**

**Nitisha Narayan<sup>1</sup>**, Anne Roberts<sup>1</sup>, Charlotte Gibbs<sup>1</sup>, Alistair Cobb<sup>1</sup>, Shaheel Chummun<sup>1</sup>, Nigel Mercer<sup>1</sup>  
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**Background:** Furlow palatoplasty is a well-established technique for reconstruction of the cleft palate that not only achieves a levator sling at the back of the soft palate, but also lengthens it.

**Aim:** To explore the outcomes following Furlow repair performed as a secondary procedure in cases of repaired cleft palate with VPD, and as a primary repair for submucous clefts at a single center over 10 years.

**Methodology:** We reviewed the database of cleft unit of the South West of England. Patients with repaired cleft palate with VPD and submucous clefts were identified. Relevant demographic data was collected. Pre and post op speech assessment was recorded by three SLTs, using the CAPS- A audit tool. Resonance and Nasal emission rated before and after surgery and compared using the traffic light format.

**Results:** 196 patients identified. Mean age was 6 years. The breakdown based on cleft type was UCLP (28%), BCLP (11.2%), CP (30.7%), SMCP (30.1%). 76.3% of the patients achieved optimum speech following Furlow procedure. Mean Velopharyngeal gap pre-op was 2.9mm, which reduced to 0.9mm post-op. The post-op videofluoroscopy was only available for 114 patients.

**Conclusions:** We found that majority of the patients undergoing Furlow procedure for speech surgery achieved optimum speech outcomes. The technique is associated with low rate of complications and quicker post-operative recovery (cf Buccal flaps). Patients with 22q11 deletion had a less favourable outcome.

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## **Is Cleft Lip repair in older children associated with higher complication rates? A post-pandemic review.**

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**Objective:** Cleft lip repair is undertaken in the U.K between the age of 3-6 months according to the "OSLO" protocol. During the COVID19 pandemic all cleft surgical activity was suspended leading to a backlog. With the return of surgical activity, we were operating on children much older than we normally would. This meant that the children were a lot more mobile, traumatising their lip repairs due to an increase in incidents of falls. We would like to present the impact of delays in cleft lip repairs at our centre, due to the COVID-19 pandemic.

**Patients and Methods:** A retrospective review of patients undergoing primary cleft lip repair was performed for patients between 2020-2022 Aug (COVID19 pandemic). To compare the outcomes, we also collected data from patients operated between 2018 and 2019. The Fisher exact test was used to explore statistical difference in surgical outcomes between the two groups of cleft lip patients.

**Results:** During the pandemic 100% of the patients undergoing primary lip repair were over the age of 6 months compared to 16% (8/50) in the pre-pandemic group. In the pandemic group, the parents of 12 children (21%) reported an incident causing trauma to the lip repair. The p value using the Fisher exact test was 0.0037, which was significant at  $p < 0.05$  confirming a higher incidence of falls in older children.

**Conclusions:** We conclude from this study that cleft lip surgery performed in older children has the potential to cause significant and unwanted complications.



## The role of removable orthodontic appliances in investigation of speech deficiencies in cleft patients

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**Background:** Tertiary care Orthodontics manages cleft palate patients who may concurrently present with speech deficiencies. In such cases, orthodontic appliances play a role in palate investigation, working closely with the Speech and Language Therapy (SLT) and surgical team. Late-unrepaired clefts are now rare, however secondary fistulae may still occur in repaired cases.

**Aims & Objectives:** This case reports a patient seen on the palatal investigation clinic to delineate the effect of the fistula or presence of palatal insufficiency and discusses the role of orthodontic appliances in diagnosis.

**Methods:** A 7-year old female with a repaired bilateral cleft lip and palate presented with a central slit fistula in the posterior hard palate measuring 6x2 mm and active speech problems involving mild hypernasal resonance with audible nasal emission. Her cleft speech characteristics were backing, lateralisation, palatisation and active nasal fricatives. The fistula raised concerns about increased nasal escape leading to hypernasality. Temporary obturation of defects have previously involved silicone putty or use of a moulded wax sheet adapting to the palatal contours. Due to posterior position of this fistula and aspiration risk, an upper removal appliance(URA) consisting of an acrylic baseplate, retained by Adams' clasps on the Es and C-Clasps on the Cs, was preferred and used for diagnostic purposes. The speech assessment was carried out with and without the URA which revealed reduction of nasal flow with obturation. A lateral video-fluoroscopy revealed an average length soft palate with middle position of the knee, good extensibility and elevation. There was complete and consistent closure at the back wall in both cases.

**Conclusions:** This indicated negligible palatal insufficiency and that surgical intervention should target fistula closure and not pharyngoplasty. The patient was listed for direct repair +/- buccinator flaps. Meanwhile, we encouraged continued wear of the URA in between her supplementary speech therapy sessions.



## Support Groups Promote Social Support in Mothers with Children Born with CL +/- P.

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Abstract

**Background:** Cleft Lip and/or Palate is the most common craniofacial condition in the UK with 1 in 700 babies being affected. The cleft journey experienced by a mother and her child can be emotionally distressing, leading to many mothers needing to access support groups. Support groups can offer support, guidance, and information to mothers throughout this challenging time.

**Aim:** As little research has been conducted solely on mothers with cleft-affected children and how support groups have promoted social support in all aspects of their lives, this study aimed to investigate how such groups promote support in mothers with children born with a cleft using the Solomon et al. (2001) framework.

**Method:** Seven mothers with cleft-affected children who had accessed a support group were recruited using purposive sampling via social media and the Cleft Lip and Palate Association (CLAPA) website. All participants took part in a 1:1, semi-structured qualitative interview. The interview transcripts were analysed using a constructivist grounded theory approach.

**Results:** Four main themes were identified: The Unknown, Shared Experiences, Life Changes and Friendship. The promotion of social support for mothers was found in all aspects of their lives. Results also identified novel findings concerning the normalisation of emotions, the offer of an abortion at the prenatal scan, and the importance of support groups for these participants.

**Conclusion:** Future directions and research opportunities of these findings will be discussed.



## **Development of a draft pathway and draft leaflet for babies diagnosed with a bifid uvula.**

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The current service reflected upon an increased number of referrals for babies born with a bifid uvula (BU), received from one hospital highlighting inequity across the region. Diagnosis may be delayed due to a lack of knowledge (Ha et al., 2013); therefore improving the knowledge base could expedite referrals (Johannes et al., 2020). If all hospitals within the region refer this cohort, referrals would increase placing higher demands on resources. We have not had the evidence base or resources to inform clinical decision-making, and support for parents/ professionals following the identification of a BU.

This project aimed to explore the evidence base and UK cleft team protocols, regarding the management of babies identified with a BU. It aimed to develop evidence-based protocols and leaflets which were relevant locally, based on current available evidence including clinical consensus on best practice.

A literature review researched the field of BU in relation to velopharyngeal dysfunction (VPD). A survey was sent to Lead Clinical Nurse Specialists and Lead Speech and Language Therapists in UK cleft teams.

Thirteen survey responses were received, representing 10 sites. All of these sites receive referrals for babies identified with a BU; there was consensus that these babies should be referred into cleft services. Literature supports that people diagnosed with a BU should be referred to cleft services for examination to exclude VPD (Fekaa et al., 2019). The literature review and surveys were amalgamated and a draft pathway and leaflet developed. Both have been shared with Paediatric Medical Teams, Midwives and Health Visitors, and with families following diagnosis of a BU.

The project has identified an area of the service where there was not consistent management across the region. This project has developed a draft pathway and leaflet based on the evidence base that balances both risk and clinical resource.



## **Ten Year Trends: Understanding the psychological needs of Cleft Psychology referrals by age group.**

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Background: Following an annual review of psychology referral data at the Welsh Centre for Cleft Lip and Palate, it was decided to look at referral trends over a 10-year period, with the aim of exploring whether identifying trends could allow for the development of targeted individual or group psychological interventions.

Method: Data was gathered for all Psychology referrals between 2012-2022. Referral data were screened and grouped by age bracket and gender, to determine the most common reasons for referral for psychological support.

Results: Trend for referrals revealed that for those under 5 years of age, the predominant referral was for behavioural concerns, followed by parental concerns. For the age group 6-11, the main reason for referrals were behavioural followed by bullying. In the 12-17 age group, the most common referral type was for appearance concerns followed by bullying. In the 18-23 age range, the primary referral type was for appearance concerns and then anxiety. For those age 24+ most referrals were for appearance concerns followed by anxiety. Procedural anxiety was a consistent referral across all age groups other than under 5's

Conclusions: Given the clear clusters of referral type by age group, there is potential for developing targeted psychological interventions. There are also indications that group interventions for behavioural concerns, bullying and appearance concerns might be beneficial.



### 3D Photographic Quantitative Imaging Biomarkers (QIB) in Cleft Lip and Palate – A Scoping Review

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**Background:** 3D photography is a fast, non-invasive and ionizing radiation-free method to capture 3D morphology of patients with cleft lip and/or palate (CLP). It provides a 3D point cloud (mesh) which can be used to quantitatively record individual patient anatomy. There has been extensive research over the last decade into its applications and implications in cleft care. A summative approach for quantifying facial appearance can be implemented as a Quantitative Imaging Biomarker (QIB), a measure used to objectively characterise pathology and clinical response to a given intervention such as surgery or orthodontics.

**Aims & Objectives:** This review aimed to systematically search the published literature for studies where 3D photography has been used in cleft care. It sought to categorise the role of 3D photography as a biomarker (burden of disease, investigative, prognostic, efficacy of intervention or diagnostic) and chart the evolution and development of each category over the last few decades.

**Methods:** Records were identified from both medical databases (Medline, Embase and Cochrane) and allied databases in imaging science (Web of Science and IEEE). 411 records were assessed against eligibility criteria and over 200 full-text articles selected for inclusion. Data were extracted relating to biomarker role, state of development, cleft pathology and interventions where relevant.

**Results & Conclusions:** This scoping review confirms the increasing adoption of 3D photography as a quantitative evaluative measure of cleft lip and palate. The most common role for this biomarker was evaluative with NAM and primary surgery procedures dominating interventions. Constructs used to evaluate the cleft deformity included symmetry, averageness, volume and shape. Moreover, there is a growing evidence base of pre- and post-operative 3D mesh data being used to quantitatively evaluate surgical outcomes, paving the way for a new facial appearance biomarker for database use.



### 3D Photography in UK Cleft Services – A Cross Sectional Survey

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**Background:** In the UK, it is common practice to record the pre-operative facial baseline and post-operative status of patients who have cleft lip and/or palate (CLP). While this is most usually undertaken using 2D photography, 3D photography offers a fast, non-invasive and ionising radiation-free method that provides a 3D point cloud with which further quantitative analysis can be undertaken. There are, however, various challenges associated with its implementation and while it has seen increased uptake globally, it is not yet standard practice in the UK.

**Aims & Objectives:** This study aimed to identify the extent to which 3D photography is used across cleft services in the UK and explore barriers to its implementation. It aimed to explore both technical and clinical aspects of its use and identify the appetite for a national protocol to guide image capture and a clinical protocol to standardise the time points at which 3D photographs are taken.

**Methods:** The survey was distributed to both clinicians and photographers across all UK regional cleft networks and was open to the whole MDT. Questions explored the prevalence of 3D photography, barriers to its uptake and a variety of technical and clinical aspects of its use, including the existence of and adherence to technical and clinical protocols.

**Results & Conclusions:** Results demonstrated variable uptake of 3D photography across UK cleft services, however, overall use remains minimal with many respondents reporting less than 20% of patients had matching pre- and post-operative 3D photographs at the time of primary lip repair, primary palate repair or at definitive rhinoplasty. Common barriers identified included lack of funding, lack of available photographers and challenges with malfunctioning equipment. There was strong response in favour of a nationalised technical and clinical protocol to standardise the capture and timings of 3D photographs for patients with CLP.



## **Development of educational resource videos on preventive oral health advice for children and young people**

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**Introduction:** In Alder Hey, work has been undertaken with the Mini Mouthcare Matters Programme. Part of this programme was to develop patient educational resource videos. The aim of these videos is to educate on oral health and how to prevent oral health diseases such as dental caries. These videos include key oral health take home messages. This poster looks at the process of the development educational resource video.

**Statement of purpose:** Evidence suggests that oral health has been closely linked to the general health and well being of the entire body. Baseline evaluation was completed at Alder Hey.

Oral health is not seen as a priority and is often thought of as a reaction to pain or problems rather than a proactive and preventable approach.

**Methods:** Following a focus group held with Alder Hey youth group forum, the criteria for video were determined.

**Next steps taken were:**

- Key messages were taken from the Evidence Based Delivering Better Oral Health Toolkit for use in development of the scripts.
- Work commenced with an outsourced company already working with Mini Mouthcare Matters national programme to develop the storyboards and help create the digital resource videos.
- Children and young people of Alder Hey hospital was included in the filming including those under the care of the Craniofacial and Cleft teams.

**Conclusion:** The hope from the development of these digital resource videos is that the key oral health messages will help promote good oral health for children and young people during their stay in the hospital, with key take-home messages that can be utilised by all family. Once launched plan to evaluate usefulness by gaining feedback from children and young people and their families.



## **Use of bespoke nasal obturators in a paediatric client group**

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**Aims:** To evaluate the impact of bespoke nasal obturators (NUGs) on velopharyngeal insufficiency (VPI) in children under the age of 11 and the short and long term use in speech therapy.

**Method:** Eight children undergoing speech therapy at the regional cleft centre assessed as likely to tolerate a NUG were selected. The age range was 3;11 to 10;5 years. Putty silicone impression material was applied in stages and the NUG design modified for this client group. Patients' speech pre and post-NUG was assessed by two CAPSA trained centre Speech and language Therapists (SLT) using the Great Ormand Street Speech assessment (GOSSPAS). Parameters assessed included hypernasality, hyponasality, audible nasal emission, nasal turbulence and facial grimace. A bespoke questionnaire was developed to evaluate SLT perceptions of the use of NUGs in therapy after 3 therapy sessions and again after 12 months.

**Results:** One patient did not tolerate impression. There was variation in the extent to which the remaining seven children wore and tolerated the NUGs in therapy, but improvement in all GOSSPAS speech parameters was recorded in the seven children when using the NUG. Barriers to using NUGs included self-fitting difficulties, retaining it in place, comfort, and limitation of materials. Three children wore the NUG consistently in therapy with their SLTs noting it facilitated therapy. Two children were still using their NUG after 12 months.

**Conclusions:** The results suggest that bespoke NUGs improve features of VPI in patients under the age of 11, and has potential to be a useful short term tool in therapy whilst patients are awaiting speech surgery. Limitations and variation in use need to be considered and discussed as a cleft team when triaging this age group. Psychology input is required to expand the knowledge of barriers to longer term use.



## **A Comparison of 2 and 5 Year Speech Outcomes in Children with Cleft Palate**

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Background: In the UK speech outcome data is routinely collected for all children born with cleft palate at the ages of 3 and 5 years. At 5 years speech is measured against agreed national standards including Standard 1 (S1): The achievement of speech with no evidence of a structurally related problem and no cleft speech characteristics (CSCs) requiring intervention. The Trent Cleft Lip & Palate Network also collect speech outcome data at the age of 2 years. It is not known, currently, if the data collected at 2 years of age can reliably predict a positive outcome at 5 years.

Aims & Objectives: To investigate whether speech outcome data collected at 2 years can predict the outcome at 5 years.

Method: A retrospective audit of speech outcome data for children with cleft palate born in the Trent region in 2012, 2013 and 2014 was completed. Outcomes were measured against S1 of the national audit outcomes at 5 years. 'Amber outcomes' (minimal VPD and/or minor residual/obligatory anterior CSCs) were also counted as 'positive outcomes'.

Results/Conclusions: Children who met S1 at 2 years had an 84% chance of continuing to meet S1 and a 93% chance of a positive outcome at 5 years.

Children who did not meet S1 at 2 years had a 48% chance of meeting S1 and a 64% chance of a positive outcome at 5 years.

This suggests that a positive 2-year outcome is likely to be a good predictor of a continued positive outcome at 5 years. The author concludes that 2-year speech assessment data is a useful tool to support early identification of children who are likely to require additional intervention in order to achieve a positive speech outcome.



## **Piloting an oral health intervention to support parents of young children with a cleft**

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Background: Children born with cleft lip and/or palate (CL+/-P) are at higher risk of developing dental caries. Regional audit data for 3-year-olds born with CLP in 2018 reported 30% (18) with dental caries. Historically within the North West North Wales Network (NWNWN), Clinical Nurse Specialists (CNS'S) followed National Nursing Standards of Care (NNSC) to provide oral health advice. Due to Covid related restrictions and a period of no leadership within the team, adherence to these Standards had lapsed. Development of an intervention was considered appropriate.

Aim: A pilot study to guide CNS provision of oral health advice during home visits.

Objectives: Develop a tailored aide memoir to guide oral health advice during CNS home visits.

Provide an oral health pack.

Record completion of the NNSC at the end of each 12-month visit.

Method: An aide memoire mirroring national oral health guidance was produced. Following agreement between CNS's across the Network, oral health information was provided to families in a timely manner alongside a re-introduction of the NNSC.

Results: The pilot study was conducted. The aide memoire supported advice relating to brushing, diet and dental registration. The oral health packs were given, for example when weaning was discussed. CNS's and dental clinicians highlighted some changes were required to the aide memoire and these are being addressed.

Conclusion: The pilot study has successfully introduced tailored provision of oral health advice and packs. Achievement of Standards will form part of a longer-term intervention with the improved aide memoire. A questionnaire for use at the 18-month assessment clinic to measure parents recall of early advice whilst also allowing the opportunity for parents to provide feedback will be developed. Dental audit data will be collected at aged 3 and 5 years to report oral health and allow further conclusions to be drawn from the intervention.

