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Annual Scientific Meeting & CEN Day
30 April - 2 May 2025, Crowne Plaza, Newcastle

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Abstract Book

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Free Paper Session - Clinical Outcomes

'For The Record': an artistic project reflecting on cleft care from baby to adulthood

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Background: 2024 marked the twenty year anniversary of The Spires Cleft Centre, a twin site service based in Oxford and Salisbury. The team wondered what it could have been like for a family to have experienced care across two decades, and what we could learn from their unique journey.

Aims and Objectives: To enable a family to open and honestly share their recollections by working alongside creative artists to capture their experiences.

Methods: Mum, Sharon, and son, Connor, viewed hospital records and documents to build a reflective account of their treatment. Stephanie Jalland, Creative Facilitator, and Jason Dimmock, Medical Photographer, worked with the family to share their encounter and to celebrate who they have become.

Stephanie voices their experiences in a twenty minute presentation with a series of portraits capturing their identity now. "How does it feel to see your baby change, to hear their voice alter, to hand them over for surgery? How would it feel to see your own face as a baby before surgery, and to trace changes to you throughout your childhood?"

Conclusion: One family's recollections of and responses to cleft care from birth to adulthood are shared in an insightful spoken presentation, accompanied by a series of portraits of mother and son.

Many thanks to: Sharon and Connor Dean for sharing their experiences. We are grateful to Salisbury Stars Appeal and Oxford Hospitals Charity for their generous sponsorship of this project.

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The Ideal Timing of Palate Surgery – The Northeast of England Experience

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Background: The Timing of Primary Surgery trial explored outcomes with palatal closure at 6 or 12 months. Patients who were operated on at 6 months were less likely to have symptoms of velopharyngeal incompetence (VPI) but more likely to undergo secondary surgery to achieve that. Follow-up for this trial was only until the children were 5 years old.

Aim: To determine if VPI rates at 10-years of age are different in those operated on at 6 versus 12 months and to compare rates of secondary surgery between both groups.

Methodology: Patients randomised to either group in the TOPS trial in a single UK centre with 10-year speech data were included. These were all non-syndromic patients with a diagnosis of isolated cleft palate. VPI was measured by calculating a velopharyngeal composite (VPC) sum score based on measures of hypernasality, nasal emission or turbulence, and presence of non-oral or passive cleft speech characteristics. A VPC sum of 2 was counted as VPI, and 0 or 1 as no VPI. The fisher exact test was used for statistical analysis.

Results: 29 patients had 10 year follow up. 17 underwent palate repair at 6 months (59%) of age and 12 at 12 months (41%). At 10 years no patients from the 6 month group had VPI (0%). In the 12 month group 2 had VPI (17%). This was not statistically significant ($p>0.05$). In the 6 month group 4 patients underwent secondary surgery. In the 12 month group 1 patient underwent secondary surgery. This was not statistically significant ($p>0.05$).

Conclusion: Both groups continued to present with signs of VPI beyond 5 years requiring secondary surgery. There is no statistically significant difference in VPC scores between the 6- and 12-month groups. Secondary surgery rates were higher in the 6-month group but this was not statistically significant.

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Early hearing outcomes of children born with an orofacial cleft in England

Dr Sophie Butterworth[1], Dr Kate Fitzsimons[1], Ms Sinéad Davis[2], Ms Victoria Parfect[3], Mr Jason Powell[4], Ms Jibby Medina[1], Prof Jan Van der Meulen[1], Mr Craig Russell[1]
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Introduction: The Newborn Hearing Screening Programme (NHSP), commissioned by NHS England, is responsible for hearing loss detection in newborns. Early detection of hearing loss and timely intervention can improve speech and language skills. The Cleft Registry and Audit NEtwork (CRANE) records were linked to the NHSP to determine hearing status among children born with a cleft.

Aims:

1. To determine the percentage of children with cleft lip/palate (CL/P) who received an audiology assessment.
2. To determine the percentage of children with CL/P who had permanent or conductive temporary hearing loss.

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. Completion of an audiological assessment and audiological outcomes were analysed according to cleft type, sex and syndromic status using Chi-Square tests.

Results: Of 11,574 children linked to an NHSP record, 7,116 (61%) received an audiological assessment. This varied according to cleft type ($p<0.001$) and syndromic status ($p<0.001$) but not sex ($p=0.749$). Of these children, 3,351 (47%) had satisfactory hearing recorded in both ears, 2,721 (38%) had hearing loss identified, and in 1,044 (15%) hearing status had not yet been determined. The proportion of children with satisfactory hearing varied significantly by cleft type ($p<0.001$). Permanent childhood hearing loss was identified among 268 (4%) children and bilateral conductive temporary hearing loss was identified among 1,870 (26%) children.

Conclusion: Over 90% of children with CL and >50% of children with CP+/-L had satisfactory hearing based on their audiology assessment or newborn hearing screening result. Not all children with a cleft were referred appropriately for audiological assessment. Among those who were assessed, 1 in 4 had conductive temporary hearing loss and 1 in 25 had permanent hearing loss (compared with 1-2 per 1000 in the UK).

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Alveolar Bone Graft Outcomes: Timing of Dental Extractions Across Multiple Sites in the UK

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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[1]. Extractions can be done ahead of the ABG procedure to maximise oral mucosal integrity , or at the time of surgery. Anecdotally, different sites within the UK have different protocol regarding extraction timings. Success of the ABG is evaluated radiographically approximately 6 months after the procedure[2].

Aims and Objectives:

1- To assess the outcome (Kindelan score) of all ABG's undertaken between January 2020 and January 2024 at participating UK cleft services

2- To ascertain whether dental extractions were required, the reason for extraction and subsequent timing of extraction.
3- To ascertain whether expansion was carried out.
4- To compare different ABG extraction protocol across participating cleft services.

Standard: To ascertain whether all participating cleft services meet the locally agreed criteria of 90% Kindelan 1 or 2 regardless of extraction protocol.

Methodology: A retrospective audit of the patient pool via the cleft data coordinators 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: Three Hospitals participated in data collection. Hospital A had 115 ABG's in 104 patients. The ABG success rate (Kindelan 1 or 2) was 88%. 87 patients had extractions, with 85 being at the time of surgery. Hospital B had 6 ABG's in 6 patients. The ABG success rate was 100%. 3 patients had extractions, all at the ABG. Hospital C did 130 ABG's in 104 patients. The ABG success rate was 99%. 84 patients had extractions, 40 at the time, 24 before, 20 before and at time. Extraction protocol varies across the UK.

References:
1. Gillgrass T. The orthodontic management of patients with cleft lip and palate: from birth to the late mixed dentition. Br Dent J. 2023 Jun;234(12):873-880. doi: 10.1038/s41415-023-5955-x. Epub 2023 Jun 23. PMID: 37349434.

2. NHS England. NHS standard contract for cleft lip and/ or palate services including non-cleft velopharyngeal dysfunction. https://www.england.nhs.uk/wp-content/uploads/2013/06/d07-cleft-lip.pdf (08/01/2023).

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Endoscopic craniosynostosis surgery: 10 year experience from India and the Middle East

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Introduction: Craniosynostosis results from premature fusion of the cranial sutures. There has been an evolution of surgical techniques from extensive open procedures to minimally-invasive. The senior authors introduced the endoscopic technique 2014 in Bangalore, India and then in 2021 in Dubai. The two teams are continuing to offer the technique to their respective patients.

Aims: This study aims to compare the experience of the endoscopic craniosynostosis technique from two different geographic regions and investigate surgical outcomes.

Methods: A retrospective case series of 86 non-syndromic craniosynostosis (India 66 and Dubai 20) patients with uni-coronal (26), sagittal (13), bicoronal (10), fronto-sphenoidal (4) and metopic craniosynostoses (33) was corrected endoscopically and followed up with customized cranial helmet. Pre and post-operative photography along with anthropometric measurements were taken. Both geographical groups were compared for outcomes.

Results: The mean age of all patients at the time of surgery was 101(90-117) days, mean duration of surgery was 70 minutes (38-129) mean blood loss was 120 ml(100-150), and mean duration of hospital stay 4 days(4-5). No complications and mortality were reported. Refusion of sutures occurred in 1 unicoronal patient. Mean number of helmets was 2(1-3). Patients in the Dubai group stayed longer in hospital, with a higher need for blood transfusion. The Dubai patient group consisted of multiple nationalities and racial types.

Best outcomes were seen in sagittal, bicoronal and metopic craniosynostosis, where the vectors of movement are uni-directional. In uni-coronal and fronto-sphenoidal craniosynostosis, a technical modification of releasing the lateral orbit and sphenoid wing is proposed. In patients with delayed surgery near the 6 month borderline age, additional barrel staves and osteotomies are recommended.

Conclusion: This multi-centre case series has demonstrated that endoscopic craniosynostosis surgery is safe, effective, and reliable. The technique can be applied to all forms of non-syndromic craniosynostosis in multiple ethnic groups.

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Exploring sleep and language outcomes in children with cleft lip/palate using national cohort data

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Background: Sleep is known to impact language development in young children. We know that children with cleft lip and palate are at risk of both disrupted sleep behaviour and language difficulties, but there is little research in this population into the relationship between the two.
Aim
To explore parental report of both sleep behaviour and language development from age 18-months to 5-years.

Method: Data were gathered from responses to parental questionnaires from the Cleft Collective Cohort Study. Data from questions relating to sleep or night-time behaviours were synthesised and measures of concern about sleep analysed at 18-months, 3-years, and 5-years of age. Qualitative comments were also considered. Sleep data were compared across the three ages and across cleft phenotype, syndromic status, and diagnosis of Robin Sequence (RS). Ordinal measures of reported hours of sleep were correlated with parental report of language.

Results: Over one third of parents reported concern with sleep across all ages. There were no group differences between the cleft phenotypes; nor did those with additional syndromic diagnoses report worse sleep. Statistically significant differences with large effect sizes were noted between those with RS and those with isolated cleft palate at 3-and 5-years ($p=.008$, $r=.574$; $p=.016$, $r=.573$).

Reports of sufficient hours of sleep over a 24-hour period correlated with language outcomes at all ages. The strongest correlation was seen at 5-years (τ (254) =.425, $p<.001$) and this relationship remained significant after controlling for confounders.

Discussion: High levels of parental concern with regard to sleep were observed in this data. This did not change between 18-months and 5-years. Correlations with language development were seen as has been reported in the non-cleft population. Children born with RS were most at risk of poor sleep behaviour. Findings from this exploratory study warrant further empirical research.

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Orticochea Pharyngoplasty: a versatile treatment for cleft and non-cleft VPI. A single surgeon series.

Dr Arwa Sindi[3], Ms Imogen Underwood[2], Mrs Marie Pinkstone[1], Ms Francesca Galeota[1], Ms Anje Wessels[2], Dr Theodorus Stylianou[1], **Consultant Cleft Surgeon Patricia Rorison**[1]
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Background: In the UK, pharyngoplasty is a second line treatment for VPI after exhausting options to improve palate function. The Orticochea pharyngoplasty is a well known technique but anecdotally appears to be less popular.

Aims & objectives: We want to report on one of the largest single surgeon series of Orticochea pharyngoplasties (89) over 14 years, reporting on the outcomes and the incidence of morbidity. We also want to show that it is successful in treating VPI of different aetiologies, especially 22q11 microdeletion syndrome. Also to look for any patterns that predict different outcomes after surgery.

Methods: Retrospective case note review of consecutive cases operated by the senior author in W Midlands & North Thames Cleft Services 2008 - 2022. There was a minimum of 12 months follow up. A small proportion had screening pre and post operative sleep studies without clinical symptoms of OSA.

Pre and post operative speech samples were anonymised and randomised and analysed by modified consensus listening (Ref1) The CAPS-A parameters of hypernasality, hyponasality, audible nasal emission, nasal turbulence and passive cleft speech characteristics are reported.

Results: Statistical differences in pre- and postoperative scores were tested using the Wilcoxon matched-pairs signed-ranks test. Inter and intra-rater reliability using weighted Cohen κ. Statistically significant differences were found between pre- and post-operative scores for the entire cohort. Hypernasality ($P<0.001$), nasal emission ($P<0.038$), turbulence ($P<0.034$) and CSCs ($P<0.005$). We will also present further analysis of the different patient groups.

Ref 1. Ahl R and Harding-Bell A, Comparing methodologies in a series of speech outcome studies: challenges and lessons learned. Cleft Palate Craniofacial J. 2018;55(1):35-44

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The 'KFC' multimodal assessment of alveolar bone graft outcomes: beyond the Kindelan score

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Background: Alveolar bone grafting aims to restore local anatomy, stabilise the maxillary arch, enable closure of an oronasal fistula (if present), facilitate eruption of the permeant canine tooth and provide an environment for long term tooth survival. Conventionally, ABG outcomes are evaluated using the Kindelan grading system, which has notable limitations. There is need for a more nuanced approach to comprehensively assess ABG outcomes.

Aims & Objectives: This quality improvement project aims to develop a multimodal assessment system for ABG outcomes by incorporating additional patient-centric measures to provide a more complete, holistic and informative tool for clinical use. The KFC assessment system comprises: Kindelan score for each bone graft ('K'), the presence of a residual Fistula ('F'), and eruption status of the permanent Canine by the age of 15 years ('C').

Methods: Data were collected prospectively over a 7-year period from August 2017. All ABG surgeries were performed by a single Cleft Surgeon across three sites. The Kindelan score and fistula assessment were recorded at 6 ± 2 months post-surgery. Canine eruption was assessed clinically no later than the 15-year audit.

Results: Over 100 patients met the inclusion criteria, with a median surgery age of 10.75 years (range 8-14 years). Over 95% of patients had a Kindelan score of 1 or 2. Canine eruption was spontaneous in greater than 60% of patients whilst 2% had their canine extracted and 1% required orthodontics ± traction to facilitate eruption. In 35% of patients the canines had not erupted yet. Spontaneous eruptions were common in Kindelan 1 and 2, with one spontaneous eruption in a Kindelan 3 case. The majority of patients had no fistula post-operatively.

Conclusion: The newly proposed 'KFC' grading system facilitates enhanced assessment of ABG outcomes by incorporating new clinical and patient related outcome measures alongside the historical radiological parameters.

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Free Paper Session - Patients Experience

A participatory research project to explore the lives of young people with CL/P

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Background: Participatory methods can "give voice" to underserved populations, empowering them to change how their lives are understood [1, 2]. Young people (YP) with CL/P are rarely co-researchers in cleft research, yet understanding their experiences and needs is essential for enhancing their wellbeing and improving cleft care [3].

Aims: This project used participatory photovoice research to explore the experiences and needs of YP with CL/P. The presentation will detail the research process and findings in collaboration with the co-researchers themselves. An evaluation of the impact that involvement has had on the co-researchers will also be discussed.

Method: Using participatory action research [4], 12 YP with CL/P engaged as co-researchers. A focus group defined the research aims and questions, followed by a photography training workshop. The YP then completed a PhotoVoice [5] project, collecting 145 images with explanatory paragraphs. In a creative participatory workshop, the YP collaboratively analysed this data and developed a thematic account of their findings. Two dissemination videos were produced—one addressing clinicians to improve cleft care and another aimed at educating the public and empowering other YP with CL/P. The project concluded with a focus group to evaluate its impact on the co-researchers.

Results/Conclusions: The YP developed six themes to represent their experiences: 1) memories, 2) relationships/journey, 3) treatment and feelings, 4) change, 5) perspective, and 6) opportunities and awareness. Two videos were then made. A clinician-focused video aimed to inform and catalyse cleft care improvements. A public-focused video aimed to educate, highlight resilience, and empower YP by showcasing shared experiences and positivity about living with CL/P.

References

1. Kramer-Roy D (2015).
2. Pettican A., et al. (2022).
3. Davies J, Davidson E, Harding S, Wren Y, Southby L (2025).
4. Kemmis S, McTaggart R (2005).
5. Wang CC, Yi WK, Tao ZW, Carovano K (1998).

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Smile Journey/Changing Smiles

Mrs Stacey Hussell[1]
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Introduction: I'm Stacey and I was born with a unilateral cleft lip and palate. I have worked as a medical photographer since 2005. I have had a dream for a long time about using my photography to help others born with cleft lip and/or palates. When my second child, Dylan was born in 2022 with a bilateral cleft lip and palate, I knew this was something I had to do.

Aims and Objectives: To set up a project both within my job and personally to use photography to show the beauty of cleft affected individuals, hopefully helping them feel more confident and also raising awareness.

Methods: Many meetings involving the cleft team, communication teams, information governance, psychological therapies, clinical leads and medical directors in order to get the project approved and set up.

Within my medical photography job, setting up a service whereby when patients attend the studio for their clinical photographs, they are offered the opportunity to have a portrait 'keepsake' photograph too. Privately, setting up my personal project through my business and I have also attended the Clapa adult conference, where I photographed many beautiful individuals.

Results/Conclusions: This project has been very well received Whilst working at QVH, in the first year, 32 patients had taken up the new service. I now work for another hospital (Brighton) and we are in the process of getting the project set up there too. One day I hope to have an exhibition, maybe publish a book and the dream is to fill the first page of google with beautiful images of cleft affected individuals instead of the clinical, sterile, sometimes scary images there are now.

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Using Co-production as a Tool to Improve Outcomes and Engagement

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Background: Co-production is important in healthcare because it can improve the quality of care, increase patient satisfaction, and reduce health inequalities. CLAPA delivers an effective Patient and Public Involvement (PPI) Consultancy Service that supports external partners to successfully engage with the Cleft community. CLAPA develops its internal work in partnership with its established focus groups.

Aims and Objectives: To pilot co-production as a tool to engage those with lived experience in the development and delivery of a conference for adults affected by cleft. To improve outcomes for, and engagement with, the Cleft community. To inform the development of CLAPA’s approach to PPI internally as well as identifying opportunities to enhance our PPI offer for external partners.

Methods: By working in partnership with the CLAPA’s Adult Focus Group we developed and delivered our first in-person adult conference since 2019. We utilised co-production to address the imbalance of power and enable the group to genuinely inform the development and delivery of the conference from the patient perspective. The conference was attended by 40 members of the cleft community.

Reports/Conclusions: Co-production proved successful as a tool for engagement and the outcome was the delivery of an accessible, high-quality conference. The approach enabled the focus group to have a significant influence on the development and delivery of the conference and their guidance was invaluable. Feedback from the Cleft community was positive, with 100% of attendees feeling more connected to other people affected by cleft and better informed about cleft related issues. Learning from the pilot will inform the development of the 2025 conference and CLAPA is exploring opportunities to embed principles of co-creation / co-production across other areas of its work.

References: Elwyn, G., Nelson, E., Hager, A., & Price, A. (2020). Coproduction: when users define quality. BMJ quality & safety, 29(9), 711-716.

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Creation of an online photo gallery for families receiving a diagnosis of cleft

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Traditionally within the cleft team physical photographs of babies before and after cleft surgery have been used, intended to give new and expecting parents an idea of what their child might look like before and after cleft surgery.

The way families look for and expect information to be delivered has changed, it is expected to be accessible online and instant. It has been seen how Patients and families use the Internet and social media as a readily accessible source of medical information. The team were able to direct families to gallery images on CLAPA but were aware they were not individualised to the team. There was a noted increase in families of babies with micrognathia, nasopharyngeal airways or facial clefts asking to see pictures relevant to their child's cleft condition.

Aims/ objectives: Offer an online photograph gallery showing children cared for within this cleft service, offering true representation of the children with cleft and their outcomes.
This would be accessed via the Hospital Trust website only. Updated electronic consent was needed. The images would need to be collected and sorted into categories. The Trust communications team would need to be involved to set up the gallery. To be able to offer families a true representation of the children with cleft that we treat.

Method: Identify categories of cleft conditions to be used. Write to each family individually to ask if they would consent for online gallery. Collect images, work with the Trust communications team.

Conclusions: Most families were keen to offer photographs, perceiving they were helping others and had been in their situation. Families had to be aware that images would be on the internet - accessible to all.
Expand use: Team is dual-site team with different base hospitals meaning different IT systems / communications. Add cleft stories from families.

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QuAlity of Life In Goldenhar SyNdrome (ALIGN); a PROM framework for teenagers and adults.

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Background: Goldenhar is a rare congenital syndrome affecting soft tissue, bone formation and organ systems, prevalence is approximately 1:250000-45:0000 births. In rare conditions using PROM data in clinical practice can improve both clinical outcomes and patient care (Slade et al., 2018). Unfortunately, no PROMs exist to monitor teenagers or adults affected by Goldenhar Syndrome (GS).

Aims: ALIGN aims to explore the QoL impacts of GS in adults and teenagers via survey and interview to develop a conceptual framework and create two PROMs in these populations.

Methods: A volunteer sample of 23 adults with GS (mean age 36.30; SD 14.50, 7 males, 15 females,1 non-binary) were recruited to an online survey exploring QoL issues. Results were descriptively analysed. Ten adults (mean age 28.40; SD 14.49, 3 males, 7 females) and 4 teenagers (mean age 15.75; SD.05; 1 male, 3 females) also took part in semi-structured qualitative interviews exploring QoL; reflexive thematic analysis was employed.

Results: The survey revealed that i) 72% of adults reported poor mental health, and that GS affects their relationships, ii) 76% reported being upset by their physical appearance and withdrawing in social situations, and iii) 56% reported worrying about finding a future partner. Despite these challenges, 52% stated they had a positive attitude to life. Themes identified from the teenage interviews included; I wish I was normal; why me?; other people's reactions, and the medical impact. Adult interview themes included; mindset struggle; connection breaks the isolation; society doesn't get it and medical uncertainty.

Conclusion: The conceptual frameworks for the adult and teenage QoL PROMs identified from the interviews and surveys include psychological status, self-esteem, social/interpersonal relationships, physical factors, (pain and post operative concerns). The next stage includes item generation from the frameworks and refining the putative PROM with support from patients as per FDA guidance.

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Exploring the acceptability of the CLEFT-Q Speech Scales to children and young people.

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Introduction: The CLEFT- Q is a patient reported outcome measure for people aged 8-29 born with cleft lip and palate or cleft palate assessing facial form, facial function and cleft-related quality of life. Twelve independently functioning subscales measure different elements, including speech function and speech distress. CLEFT-Q is the only cleft specific, scientifically sound measure available. However, a survey of the Lead Cleft Speech and Language Therapy (SLT) group (2023), showed that no UK Cleft SLTs use it in clinical practice. This is due to concern about the wording of the questions and whether this may have a negative impact on the feelings of people answering them.

Aim: To help SLTs understand whether their concerns are shared by their patients.
Method: A survey was developed by SLTs from (Spires, South West and Wales), the Treble Cleft Network.
Questions included in the survey were based on those reported in an international study by Klassen et al. (2020) which explored the impact of completing the CLEFT-Q scales that ask about appearance, on children and young adults. It was agreed our survey would be given to patients aged >8 years, attending clinics across the 4 sites between October 2023 to August 2024. Data was collected using Microsoft Forms.

Results: The survey was completed by 75 participants, aged 7–22 years old. Mode age-10 years old. 97% of participants either said they liked answering the questions or it was 'ok'. When asked about how the questions made them feel about their speech, 87% responded as positive or neutral.

Conclusion: This survey shows that most participants liked completing the CLEFT-Q, with a small minority reporting a negative impact. This challenges the current views of Cleft SLTs and may influence future clinical practice in the UK.

Carrie Luscombe, Joanna Waldron and Sharon Baker
January 2025

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Health inequalities in access to dental care for children with a Cleft, "HANDCLAP" Parents' voices.

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Background: Parents often visit the cleft clinic feeling upset because it is difficult to get general dental care for their child. A clear North-South divide is evident, with Cleft Services in the North of England having higher rates of patients from the most deprived quintile compared to the South. Almost 50% of patients with a cleft live in the 2 most deprived quintiles.

Aims and Objectives: The primary objective was to understand the barriers related to accessing dental care for children with a cleft from all socio-economic backgrounds.

Methods: Health Inequalities Assessment Toolkit was used to integrate an equity lens in this study. 4 parents were involved in designing of the research project prior to Ethical approval (330971/ Wales REC 4)
PPI focus group with 6 parents from diverse backgrounds was done with the help of CLAPA. Themes were identified and a visual/verbal topic guide was created for parent interviews.

INCLUDE guidance from NIHR and other innovations were used to recruit parents from under-served groups. Research team members were from different cultures and spoke 7 different languages. Initial contact was made by a cleft team member familiar to the family. Purposive sampling included all deprivation groups, minimal-English speaking parents, parents of children with complex medical history etc. Semi-structured interviews of 18 parents of 7-9 yr old children were conducted as per parents' choice of time and method. Braun and Clarke thematic analysis was carried out.

Results: The main barriers for parents to access dental care were - Communication, Lack of trust, "Entry" and "effective" access, parent priorities and Individual parent barriers.

Conclusions: The results are being discussed with all stakeholders. Some of the action plans to translate this research include process mapping communications, making a social media video for parents, planning a feasibility study for personalised dental care.

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Is YouTube a valuable information resource for orthognathic surgery in cleft lip and palate patients?

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Background: The way patients access information is predominantly digital and value information available to them online as their primary information source. One of the most popular websites is YouTube.

Aims & Objectives: To assess the quality of the information available on YouTube for patients with cleft lip and palate planning to undergo orthognathic surgery.

Methods: YouTube was searched by typing in keywords relating to orthognathic surgery and cleft with use of the following search terms; 'cleft lip palate orthognathic surgery'; 'cleft orthognathic surgery'; 'orthognathic surgery in cleft patients.' Inclusion criteria included videos related to orthognathic surgery only in those who have cleft lip and palate; that were in English language (subtitles or spoken) and information available in written or spoken form. The top 50 videos were chosen by sorting in descending order by number of views. Overall, only 35 videos were found to be relevant and were included in the study. Data was collected on Excel spreadsheet collating number of views, dislikes and likes, audience, authorship and sources. These videos were classified into 'poor', 'moderate' and 'excellent' for their quality of content and where text was available, ChatGPT was used to determine the UK reading age.

Results: An inter-examiner relatability score gave almost perfect agreement between the two assessors (k =0.88). The top 35 videos had combined total of 385,586 views. The majority of the videos (60%) involved patients describing their own experiences. When classifying the quality of the videos, only 7% were deemed of excellent quality, with 26% and 67% of moderate and poor quality respectively.

Conclusion: The content available to cleft lip and palate patients relating to orthognathic surgery on YouTube is highly variable and of substandard quality. Patients should be signposted to relevant information available on Cleft lip and Palate Association and British Orthodontic Society websites.

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"What I want you to know" – a photovoice study of women's stories of cleft

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Background: Most psychosocial cleft lip and/or palate (CL/P) research concerns children, parents or adults reflecting back on their childhood. However, recent work has indicated that adults born with CL/P may have unique residual needs relating to societal norms and pressures as well as satisfaction with treatment and early experiences. Some research highlights the potential role of gender in differing psychosocial outcomes and experiences.

Method: Photovoice methodology was employed, with participants (n = 14, mean age = 48, range = 20-72) submitting photographs to represent parts of their story of being a woman with CL/P. Semi-structured narrative interviews were guided by the photographs and transcribed for narrative analysis.

Results: Participants differed in how much their CL/P impacts on their day-to-day functioning. However, all participants told stories of sacrifices and compensatory strategies present in their lives that they do not believe are understood by their non-cleft-affected peers or by professionals. Societal pressures on women were discussed, as was self-advocacy, social insecurity and the CL/P journey as ‘far from over’ following the end of treatment. Most participants discussed their beliefs about their choices of career, relationships and other significant life decisions being impacted by their CL/P. Learning to manage the residual impact of CL/P was a salient theme, whereby participants expressed the importance of finding supportive, trustworthy social connections, making sense of traumas and engaging in peer networks to reduce feelings of difference.

Conclusions: The findings of this study enrich previous suggestions that women born with CL/P still experience psychosocial difficulties which should be held in mind by professionals when they return to treatment. Trauma-informed, holistic care, considering ways in which individuals cope with and make sense of difficult experiences and decisions regarding their lives and treatment is important in ensuring that needs are understood in an adult context and met appropriately.

Free Paper Session - Innovation/Technology

Application of 3D Shape analysis to evaluate morphometry of right vs left-sided Unilateral Cleft Lip

Miss Ambika Chadha[1], Mr Will Raby-Smith, Miss Kanwalraj Moar, Mr Athanasios Papaioannou, Mr David Chong, Mr Piet Haers
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Background: Published literature suggests that there are differences between the presentation of right vs. left-sided Unilateral Cleft Lips (UCL). This hypothesis has never, however, been demonstrated. This study sought to use shape analysis to map the UCL phenotype and to determine objectively whether there are morphometric differences between right- vs. left-sided UCLs.

Aims:
1. To describe the foundations of 3D Morphable Models (3DMM) as a contemporary method of facial shape analysis
2. To demonstrate the feasibility of a 3DMM for UCL and acceptable model
3. parameters.
4. To demonstrate a quantitative depiction of the UCL phenotypic spectrum
5. To demonstrate evidence for a difference between the morphology of right sided- versus left-sided UCL

Methods: Ethical approval was granted to analyse 86 3D Photographs of UCL prior to lip repair by a single surgeon. Right-sided UCL photos were flipped. The nasolabial region was cropped, textural and colour information removed and mesh data exported. 31 landmarks were placed on the mesh based on the Fisher approach to UCL repair. Sparse and dense correspondence was induced with a template mesh, followed by non-rigid registration methods to generate a similarity coefficient. These values were represented graphically. Principal Component Analysis was used to depict variance in UCL shape. Manifold visualisation was used to determine the existence of shape differences between right vs left-sided UCL

Results: 56 High quality 3D images were selected. The resulting 3D Morphable Model (3DMM) of UCL demonstrated satisfactory compactness, generalisation and specificity. Mean shape and variation for a UCL were qualitatively generated for the first 5 shape Eigenvectors and demonstrated plausibility. The UCL3DMM was able to correctly guess a L-sided cleft 78% of the time, and a right-sided cleft 64% of the time.

Conclusion: Given that UCL laterality is a binary outcome, the findings above warrant further exploration of cleft laterality.

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Analysis of Treble Cleft Pierre Robin Sequence Pathways: An opportunity for consensus?

Ms Helen Moreland[2], Ms Nicola Goldhawk[1], Ms Rachel Green[3], Ms Michelle Jones[4], Mr Neil Brierley[4], **Mr Matt Fell**[1]
[1]South Wales Cleft Service, Swansea, Wales, [2]Spires Cleft Service, Salisbury, England, [3]South West Cleft Service, Bristol, England, [4]West Midlands Cleft Service, Birmingham, England

Background: Patients born with Pierre Robin Sequence (PRS) are challenging to diagnose, investigate and treat because of their complexity and variability. There has been much debate about the best approach to PRS and despite recent international consensus efforts, there remains significant variation in practice.

Aims: To review current practice in our Treble Cleft services (Spires, West Midlands, Southwest and South Wales).

Methods: Cleft team PRS protocols were analysed and data extracted into areas of diagnosis, investigation and management. To understand the nuance of the pathways, discussion was undertaken in a forum with the specialist cleft nurses. Findings were presented and discussed at the annual Treble Cleft meeting in November 2024 and an action plan agreed.

Results/Conclusions: Three teams specified diagnostic criteria of micrognathia, glossoptosis and cleft palate, whereas one team included upper airway obstruction. Sleep studies were oximetry or cardiorespiratory polysomnography rather than full polysomnography and performed at different time intervals. Time to get sleep study results varied from immediately to six weeks. Airway management was led by a mixed team of ENT/Respiratory/Cleft and the strategic use of nasopharyngeal airways was generally similar between the four cleft teams. The approach to feeding varied, with one team having a lower threshold for nasogastric tube insertion and a restriction on oral feeds, whereas the other three teams fed their PRS babies at an earlier age. There was variation in surgical timing with two services planning primary palatoplasty before 12 months and the other two services waiting until the child was at least 12 months.

An action plan was agreed to reach a consensus regarding the diagnosis of PRS in our Treble Cleft in line with recent European Guidance. We hope this will enhance our ability to compare best practice between teams and improve patient experience and outcomes.

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RoboticScope (Robotic Microscope) Assisted Primary Cleft Palate Surgery: A Pilot Retrospective Cohort Study

Mr Derek Mendonca[1], Mr Jonathan Mokhtar[2], Ms Fatima AlHammadi[2], Ms Shaikha AlMarzooqui[2]
[1]Al Jalila Children's Hospital, Dubai, United Arab Emirates, [2]Mohammed Bin Rashid University School of Health Sciences, Dubai, United Arab Emirates

Background: Conventional cleft palate surgery usually involves operating in a narrow oral cavity space with surgical loupe visualization. Today, most cleft surgeons resort to surgical microscopes to improve visualization and obtain more precise muscle dissection. The RoboticScope is a head movement-controlled system which moves the robotic arm loaded with 3D visualization technology, allowing surgeons complete freedom to use their hands for surgery.

Methods: This was a retrospective pilot analysis of eight pediatric patients, split into two cohorts of four, comparing conventional palatoplasty to RoboticScope-assisted palatoplasty performed in 2023. Patient demographics were collected, including age (in months), sex, and cleft palate classification (Veau I-III). The study employed both quantitative and qualitative variables. Variables measured included operative time, postoperative analgesia, oral intake, hospital stay and complication rates. Ergonomic evaluations were performed through surgeons documenting their feedback on comfort and surgical efficiency, including dissection and repair.

Results: RoboticScope® assisted palatoplasty averaged 28 minutes longer than the conventional method. Postoperative analgesic needs also differed: 100% (n=4) of the patients who underwent conventional palatoplasty required morphine, whereas only 50% (n=2) of the RoboticScope patients required morphine. 75% (n=3) of the RoboticScope patients demonstrated good oral intake on day one, and 50% (n=2) of the patients were discharged one day earlier than the conventional group was. No significant differences in complication rates were found, but ergonomic assessments revealed improved posture and reduced strain for surgeons utilizing the RoboticScope. Surgical advantages and technical details will be presented.

Conclusion: This study concludes that RoboticScope-assisted palatoplasty is safe, feasible, and is associated with fewer analgesic needs, better oral intake and ergonomic benefits for surgeons than to conventional palatoplasty.

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Speech and Language Therapists’ Perspectives on Using Ultrasound for Cleft Research and Practice.

Prof Joanne Cleland[1], Ms Robyn McCluskey[1], Dr Maria Cairney[1], Ms Lisa Crampin[2], Ms Linsay Campbell[2]
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Background: Ultrasound visual biofeedback has the potential to be a useful tool in Cleft Palate ± Lip care but there is little research on its effectiveness, nor on clinicians’ views on using it in research and practice[1].
Aims & Objectives: This study reports on cleft-specialist Speech and Language Therapists’ views on the acceptability of ultrasound in clinical practice and on their readiness to contribute to future clinical trials of its effectiveness.

Method: A qualitative design comprising semi-structured focus groups/interviews was used. Eleven participants took part over two focus groups and two interviews. Focus groups/interviews were recorded, transcribed verbatim, and an inductive thematic analysis was undertaken. Once complete, a deductive analysis using the theoretical framework of acceptability[2] was used to summarise the findings.

Results/Conclusions: Four themes emerged: 1. Value of ultrasound as an approach; 2. Intrinsic drawbacks of acquiring and utilising ultrasound; 3. Competence in effective performance within a clinical trial; and 4. Incentives for clinicians and patients in participation in research. Results suggest that participants were positive about the benefits of ultrasound for visualising the articulators and improving patient outcomes. Barriers to adoption included the cost of the equipment and the time to travel to appointments. Across clinical and research uses of ultrasound the need for high-quality training and networking within a community of practice were highlighted.

References

[1] J. Cleland, "Ultrasound Tongue Imaging in Research and Practice with People with Cleft Palate ± Cleft Lip," The Cleft Palate Craniofacial Journal, vol. 0, no. 0, p. 10556656231202448, 2023, doi: 10.1177/10556656231202448.
[2] M. Sekhon, M. Cartwright, and J. J. Francis, "Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework," BMC Health Services Research, vol. 17, no. 1, p. 88, 2017/01/26 2017, doi: 10.1186/s12913-017-2031-8.

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Service Evaluation of the Use of CBCT in Alveolar Bone Graft Planning at Salisbury Hospital

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[1]The Spires Cleft Centre, Salisbury, UK

Introduction: Dental Panoramic Tomograph (DPT), cleft-centered Upper Standard Occlusal (USO) and Cone-Beam Computed Tomography (CBCT) images can be taken, when justified, to aid assessment for Alveolar Bone Graft (ABG) surgery.

Objectives:
1. Ascertain the number of CBCT requests
2. Assess the radiation dose of CBCT and plain film images
3. Evaluate the justification and information obtained from the CBCT

Methods: All patients attending ABG clinics between 1/1/2023 and 31/12/2023 were included in this retrospective audit. A proforma was used for data collection (age, gender, LASHSAL; justification for and information obtained from CBCT).

The radiation dose of CBCT, DPT and USO was calculated for each patient.

Results: 35 patients attended 8 ABG clinics in 2023. Seven patients (20%) had a CBCT image taken in addition to the plain film radiographs.

The justification for CBCT request was to ascertain the size and morphology of the alveolar cleft and/or to locate the position of supernumerary teeth.

The mean value of CBCT dose was 46 (8-194) mGy, while the mean values of DPT and USO doses were 34.6 (25.8-43.4) mGy and 0.1 (0.064-0.128) mGy respectively.

The field of view for the CBCT images was 4 by 5cm^2, with the exception of 1 image (8 by 8cm^2).

CBCT images can provide additional information regarding the morphology, size and location of the alveolar cleft. In cases with supernumerary teeth, they provide accurate information about the position, shape, and relationship to adjacent structures. This can conclude whether a bone graft is required and prevent incorrect dental extractions where multiple teeth are present in the area of the cleft.

With a small field of view, CBCT has a comparable radiation dose to a DPT.

Conclusion: When justified, CBCT images provide additional information to aid planning ABG surgery and peri-operative dental extractions, without excessive radiation exposure.

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Three-dimensional exoscopic cleft palate repair – A single-centre experience

Mr Michalis Hadjiandreou[1], Mr Ahmed Elbaz[1], Miss Cheuk Nam Bertha Lee[2], Mr Venkat Ramakrishnan[1], Mr Amir Sadri[3], Mr Loshan Kangesu[1]
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Introduction: The operating microscope remains the gold-standard in cleft palate repair, however, cleft surgeons have expressed concerns regarding their cervical health after a lifetime of cleft surgery. Developments in optical and digital technology have paved the way for utilisation of the three-dimensional (3D) Exoscope in free flap reconstructive surgery, however, its application in cleft surgery has not been widely adopted yet.

Aims: A retrospective case series presenting the clinical outcomes and experience of utilising the three-dimensional exoscopic technology in cleft palate repair since 2021.

Methods: A retrospective single-centre analysis of a single-surgeon practice was performed dating from 2021 to present. 14 cleft palate procedures were undertaken using an Exoscope: 13 with the KINEVO (ZEISS); and 1 with the ORBEYE (OLYMPUS). 7 infants underwent primary repair and 7 children and adults had secondary surgery.

Results/Conclusion: In all 14 cases, there was no concerns with the duration of the procedure, complications or outcome. In 2 of the 14 cases, the surgeon switched to optical mode temporarily due to technical difficulty. The surgeon reported specific advantages of using the Exoscope such as feeling less fatigue. Disadvantages included inferiority of image quality when bleeding occurred and reduced depth of focus compared to the operating microscope.
Our initial experience of using the Exoscope for cleft palate surgery is promising. In expert hands, the learning curve has been relatively easy. Prospective studies are recommended to establish the safety of the technology in cleft palate surgery.

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Innovative use of intraoral scanners for the construction of Nasal Obturators: A Case Series

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Background: Incomplete closure of the velopharyngeal apparatus during speech, can result in hypernasality, nasal emission, and reduced speech intelligibility. These issues not only impair articulation but can also negatively impact a patient's self-confidence and psychological well-being [1]. For patients where surgical closure is not possible or where medical conditions contraindicate surgery, a removable nasal obturator serves as an effective treatment option for managing nasopharyngeal insufficiency. The use of an intraoral scanner demonstrates a significant advancement in the fabrication of such obturators.

Aims and objectives: To demonstrate the benefits of utilising digital technology, scanners and CBCT in the field of craniofacial reconstruction.

Methods: This case series explores the innovative use of intraoral scanning technology for fabricating nasal obturators in patients presenting with nasopharyngeal insufficiency. Three patients were referred to Liverpool University Dental Hospital and were identified as suitable candidates for this technique. The Primescan™ by Dentsply Sirona was used to capture a detailed 3D visualisation of the nasal cavity. The scanned data was subsequently transferred to a compatible CAD software, where the prosthetic appliance was designed to meet the functional needs of the patients.

Conclusion: Incorporating digital workflows into patient care can enable the safe fabrication of prosthetic speech appliances, allow anatomical detail to be captured accurately and reduce the discomfort associated with traditional analogue impression techniques [2]. This case series highlights the advantages of digital technology in fabricating prosthetic aids to improve speech and re-establish normal air flow during articulation.

References:
[1] McIntyre GT. Management of patients with non-syndromic clefts of the lip and/or palate part 3: from age 10 until adulthood. Dental Update. 2014 Dec 2;41(10):876–81.

[2] Popat S, Critchlow S. The restorative dentistry management of adult cleft patients: "The Adult Returner." British Dental Journal. 2023 Jun 23;234(12):906–11

Free Papers – Seeing the bigger picture

Findings from genome wide association analyses in the Cleft Collective

Prof Sarah Lewis[1], Dr Kyle Dack[1], **Prof Evie Stergiakouli**[1], Prof Jonathan Sandy[1], Dr Tom Dudding[1], Prof Kerstin Ludwig[2], Dr Sethlina Aryee[1], Ms Amy Davies[1], Dr Gemma Sharp[3], Ms Karen Ho[1], Dr Elisabeth Mangold[2], Ms Kerry Humphries[1], Dr Carlo Maj[4], Prof Yvonne Wren[1]
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Background: Genome wide association studies can identify regions of the genome which are involved in a trait of interest and have been previously used to identify several chromosomal regions and genes associated with cleft. However, the majority of previous studies have restricted their analysis to non-syndromic cleft lip with/without cleft palate.

Aims & Objectives: We set out to identify new common genetic variants associated with all orofacial clefts and with 7 cleft subtypes, and to investigate differences in genetic effects between cleft subtypes.

Methods: We conducted genome-wide association studies (GWAS) of all orofacial clefts using data on around 5 million genetic variants in 2268 cases from the Cleft Collective and 7913 population based controls. We also conducted GWAS in 7 different subgroups of OFCs and compared results across subgroups.

Results: In total we identified 27 regions showing genome wide significance, 8 of which were novel. Notable novel associations we observed mapped to ARHGEF18 and ARHGEF19 (related to cleft lip with/without palate (CL/P)), and CASC20 (related to cleft palate only (CPO)). Several novel hits are in regions previously associated with facial morphology in GWAS or are involved in key developmental processes. In addition, in a relatively small Pierre Robin Sequence sample (n=237), we identified 1 genome wide significant locus plus another 23 with suggestive evidence (p<1x10-5). The majority of the genetic variants we identified (n=15) were only associated with CL/P and not with CPO, however, a third showed similar effects in both (n=9). In addition, three genetic regions showed some weak evidence of an effect on Pierre Robin Sequence (PRS) in the opposite direction to their effect on cleft lip subgroups.

Conclusion: Our findings highlight novel genes for further investigation and show the importance of including all cleft types in GWAS studies.

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Copy Number Variants Linked to Neurodevelopmental Disorders and their Implications for Cleft Lip and/or Palate

Dr Rachel Blakey[1,2,3], Dr Alexandros Rammos[1,2,3], Miss Amy Davies[1], Prof Yvonne Wren[1], Mrs Kerry Humphries[1], Prof Sarah J Lewis[1,2], Dr Gemma C Sharp[4], Prof Michael J Owen[5], Prof Marianne B M van den Bree[5], **Prof Evie Stergiakouli**[1,2,3]

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Background: There is evidence of an increased prevalence of neurodevelopmental and behavioural problems among children born with cleft lip and/or palate (CL/P) (Berman et al. 2024). It is possible that this is partially explained by genetic overlap between CL/P and neurodevelopmental disorders. Copy number variants (CNVs) are duplications or deletions in segments of chromosomal DNA that are greater than 1 kilobase (kb) in size and have been found to be strongly associated with neurodevelopmental disorders (Kendall et al, 2019). Neurodevelopmental CNVs have not been systematically investigated in children born with CL/P.

Aims & Objectives : In this study, we aimed to determine the prevalence of neurodevelopmental CNVs and explore their links to neurodevelopmental and behavioural problems in children born with CL/P.
Methods: Using data from the Cleft Collective, we determined the rates of neurodevelopmental CNVs in all children born with CL/P, and by cleft type, and compared them to four general population comparison cohorts. We tested if children born with CL/P and neurodevelopmental CNVs are at higher risk of developmental delays, as determined by trajectories of scores on the Ages and Stages Questionnaire, and behavioural problems, as determined by the Strengths and Difficulties Questionnaire, than those born with CL/P but without neurodevelopmental CNVs.

Results: Children born with CL/P had a higher prevalence of neurodevelopmental CNVs than participants in four general population comparison groups (3.7% vs ~1.7%-2.3%, $p<0.002$) and were more likely to experience developmental delays and behavioural problems by age 5. Children born with cleft palate only were 2.98 times more likely to have a neurodevelopmental CNV (95%CIs= 1.50-6.59, $p=0.03$) compared to children with cleft lip only. Genetic testing to ascertain the presence of neurodevelopmental CNVs might be helpful in early identification of developmental needs in some children born with CL/P.

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UK Survey: Exposure to cleft during surgical training and attitudes towards a career in cleft.

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Background: Cleft surgeons in the UK come from a range of specialty backgrounds. Anecdotally, exposure to cleft surgery during training varies considerably. This may influence perceptions of a career in cleft surgery.

Aims: To provide an insight into exposure to cleft during surgical training, and perceptions of a career in cleft surgery amongst surgical trainees.

Methods: An electronic survey was distributed to trainees in Oral and Maxillofacial (OMFS), Ear, Nose and Throat (ENT) and Plastic Surgery in the UK (UK). The survey was divided into trainee background, cleft exposure during training and perceptions of a career in cleft surgery.

Results: There were 47 responses. Most respondents were Plastic Surgery trainees with representation of all registrar training grades from ST3-ST8. There were also submissions from OMFS and ENT surgeons. Trainees described a disparity in access to cleft surgery during training across Deaneries. Some trainees reported having to obtain cleft experience outside of their home Deanery, which in one instance required annual leave. Approximately a quarter of trainees found it difficult to obtain their indicative numbers, citing service provision; cancelled lists; division of services between plastic surgery, ENT, and OMFS; and unsupportive training programme directors as potential reasons for this. Funding for cleft-specific courses was not available to all trainees. Although a third of respondents were interested in a career in cleft, only one-third of this group reported intending to pursue this interest. Many trainees perceived significant challenges that might explain this. These included lack of training opportunities and limited consultant post availability.

Conclusions: We have found that exposure to cleft during surgical training is currently inconsistent across UK. In addition to barriers during training, trainees perceive a range of obstacles to pursuing a career in cleft surgery following the completion of training.

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A Single-Centre 15-Year Review of Surgical Techniques for Lip Augmentation in Patients with Cleft Lip

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Introduction: Non-surgical methods of lip augmentation for patients born with a history of cleft lip +/- palate both within the NHS and on the high street have become increasingly popular. However access to lip filler on the NHS for these varies widely across the UK and there are cost implications for providing this service.

Aims & Objectives: This presentation discusses a 15-year experience at Newcastle's Royal Victoria Infirmary of surgical lip augmentation with fat and dermal grafting for lip augmentation in cleft lip and palate patients. The aim of this paper is to provide a cost-based analysis of surgical augmentation and compare this to the extrapolated costs of non-surgical techniques, based on a recent study by Rivers et al. (2021).
Methods: A retrospective review of 45 patients with a history of cleft lip +/- palate (aged 16-52 years) who underwent a total of 76 lip augmentation procedures. Procedure type, associated surgeries, length of inpatient stay, number of outpatient appointments, and nature of repeat/revision procedures were recorded. A full cost based analysis of lipofilling and dermal grafting will be performed using data provided by the trust coding and finance departments. In comparison, extrapolated costs of a non-surgical augmentation service will be calculated from Rivers et al's paper based on number of outpatient appointments, volume of lip filler, and number of repeat procedures.

Results/Conclusion: This paper will provide an overview of both surgical and non surgical lip augmentation in patients born with a cleft lip +/- palate and will provide a cost based analysis for other services considering either procedure.

Reference:
Rivers, C.M. et al. (2023) 'Use of hyaluronic acid filler in patients with secondary cleft lip deformity', The Cleft Palate Craniofacial Journal, 61(7), pp. 1233–1237. doi:10.1177/10556656231161981

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Relative socioeconomic deprivation in children with cleft lip and/or palate

Dr Kate Fitzsimons[1], Dr Abhishek Dixit[1], Dr Sophie Butterworth[1], Ms Jibby Medina[1], Prof Jan van der Meulen[1], Mr Craig Russell[1,2]
[1]Royal College of Surgeons of England, London, UK, [2]Royal Hospital for Sick Children, Glasgow, Scotland

Background: The Cleft Registry and Audit NEtwork (CRANE) Database recently assigned Indices of Deprivation (IoD) scores to CRANE-consented children to describe the relative socio-economic deprivation of this clinical cohort.

Aims & Objectives: To determine whether 1) children with a cleft are more likely to be born and live in the most deprived areas than the general population, and 2) the percentage of children living in the most deprived areas varies between cleft services.

Methods: English IoD were used to assign IoD scores and quintiles to CRANE-consented children, born 2014-2023, with a valid English postcode of residence. For comparison, the IoD quintile distribution was obtained for English live births occurring 2015-2022. Descriptive statistics were calculated as number (%) of cleft cases within each IoD quintile. Chi-Square analyses were used to determine whether the distribution of cleft cases across quintiles of deprivation differed significantly to live births in the general population and between Cleft Services.

Results: 6,515 (89%) eligible CRANE-consented children had IoD scores. Children living in the most deprived areas (Quintile 1) were over-represented (26%) and those in the least deprived areas (Quintile 5) were under-represented (16%). However, there were no significant differences compared to the distribution of live births in the general population in England ($p=0.133$). The percentage of cleft patients living in the most deprived areas varied across Cleft Services (11% to 47%, $p<0.001$), with Services in the North of England having higher rates of patients from the most deprived quintile compared to those in the South.

Conclusions: Children with a cleft lip and/or palate appear to be no more likely to live in the most deprived areas than the general population. The association between relative deprivation and cleft-related outcomes should be explored.

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An audit to ascertain whether cleft patients undergoing orthodontic treatment are attending routine dental care

Dr Batol Nahas[1], **Miss Mary Bussell**[1]
[1]The Spires Cleft Centre, Salisbury, UK

Introduction: All patients undergoing a course of orthodontic treatment should have a healthy dentition and excellent level of oral hygiene.

The General Dental Practitioner (GDP) plays an important role in monitoring the development of the occlusion, educating the patient on oral hygiene and dietary advice, and treating dental disease. The GDP may be asked to carry out orthodontic extractions.

Those patients without regular dental care are at risk of dental disease, prolonged orthodontic treatment, and an inferior outcome long-term.

Objectives:
1. Ascertain whether cleft patients, undergoing active orthodontic treatment, are attending routine dental care
2. Confirm the setting of dental care (NHS, Private, Special Care)

Standard: 100% of patients, undergoing active orthodontic treatment, should be registered with a GDP and have been seen within the past 12 months

Methods: A prospective audit was carried out over a 6-week period, between October and December 2024. Patients undergoing active orthodontic treatment and under the care of the Spires Cleft Centre, at Salisbury District Hospital were invited to participate. A questionnaire was used for data collection.

Results: Fifty-six patients completed the questionnaire. Forty-six (82%) of these patients reported being registered with a GDP.

Thirty-three patients (59%) reported having been seen within the past 6 months; and 9 patients (16%) within the past 6 - 12 months. Six patients (11%) were seen over a year ago, while seven patients (12%) were seen over two years ago. One patient (2%) reported having never visited a dentist.
Thirty-eight (68%) patients are seen by an NHS dentist.

Conclusion: The audit standard was not met: however, the majority of Spires Cleft Centre patients, undergoing active orthodontic treatment, do have access to regular dental care. Patients are most frequently seen in an NHS setting, and appear to attend dental check-ups every 6-months.

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Body Image Disturbance in Teenage and Adult Cleft Populations: A Preliminary Study

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[1]National Cleft Surgical Service for Scotland, Glasgow, Scotland

Background: Body Dysmorphic Disorder (BDD) is a pathological preoccupation with an imagined or slight physical defect of one's body, to the point of causing significant stress or behavioural impairment in several areas (Bjornsson, 2010). In the general population, BDD will affect around 1 person in 50; its prevalence in individuals treated for cleft lip and/or palate are currently unknown. In health care settings, BDD has been evidenced to occur in a higher proportion of people, i.e. cosmetic surgery, cosmetic dental, orthodontics, or psychiatric settings. BDD is most prevalent in teenagers and young adults, and can affect both men and woman. BDD has yet to be investigated in cleft populations, which this project will address.

Methods: This paper presents a protocol for a literature review and national empirical study, exploring the prevalence of BDD in cleft populations. The National Cleft Surgical Service for Scotland (NCSSS) will ask returning adults and teenagers to complete Body Image Disturbance Questionnaire (BIDQ) as part of their existing psychological questionnaire battery on the Adult Pathway. Alongside a qualitative assessment conducted by qualified Clinical Psychologists, and controlling for impacting covariates, this project aims to explore prevalence of BDD in adult cleft populations.

Results: This study will determine either;
H(1) Patients with a cleft lip and/or palate show increased scores on the BIDQ compared to population data
H(0) Patients with a cleft lip and/or palate show no increase in scores on the BIDQ compared to population data

Discussion: When assessing psychological variables prior to elective cleft surgical interventions, BDD is a vital consideration. Appropriate identification and treatment of BDD would be essential to ensuring optimal outcomes in both cleft surgical intervention and the patient's psychological wellbeing.

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Evaluation of Cleft Lip/Palate Education and Undergraduate Preparedness in UK Dental School Curricula

Dr Joshua Kennedy[1], Prof Martin Ashley[2]
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Background/Introduction: Cleft lip and palate (CLP) is one of the most common congenital craniofacial anomalies, requiring a multidisciplinary approach for effective management. Undergraduate dental education is essential in equipping future dental professionals to understand and contribute to such care. However, limited research exists on the extent and quality of CLP education in UK dental school curricula. While this study focuses on dental students, enhancing the education of all members of the dental team—including dental hygiene, therapy, and nursing students— would be more impactful.

Aims & Objectives: This study evaluates the current teaching of CLP in UK dental schools, assesses undergraduate preparedness for managing CLP patients, and explores the need for a standardised CLP educational package.

Methods: A survey was distributed via the British Dental Association Student Committee to all UK dental schools. Sixteen institutions responded, with the majority of participants being final-year (BDS 5) students. The survey covered topics such as teaching quantity and format, student confidence in CLP knowledge, and perceptions of exposure adequacy in CLP education.

Results/Conclusions: Findings reveal that undergraduate students perceive CLP education as insufficient within current curricula. Students expressed a strong need for increased exposure to CLP-related topics. Implementing a standardised CLP educational package could address these gaps, ensuring equitable access across UK dental schools. Expanding this package to cover other multidisciplinary team (MDT) areas—such as hypodontia, developmental disorders, head and neck cancer, orthognathic surgery, temporomandibular disorders, and dental trauma—could further enhance dental education. Collaboration among Clinical Excellence Networks (CENs) could streamline the development and delivery of such resources.

This study provides valuable insights for curriculum developers, including the Dental Schools Council and General Dental Council, highlighting the importance of strengthening CLP education to prepare graduates to deliver comprehensive patient care.

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Free Papers - Policies and Protocols Theme

Cleft Palate Identification Poster: inaugural project of Nurses CEN Innovation, Development & Evidence-Based Practice Group

Mrs Jane Sibley[1], G Geden [2], G Blackwood [2], C Lewis[2], H Sahunta[2], L McDowall[2], C MacDonald[2], S Keenan[2], C Reddy[2], C Walton[2], B Willshire[2], E Dixey[2], L Pattison[2], S Stringer[2], A Habel[2], C Marsh[2]

[1]Spires Cleft Centre, Oxford, Oxford, UK, [2] Cleft Nurses CEN Innovation, Development and Evidence-based Practice Group 2024

Background:Delayed detection of cleft palate continues to be prevalent in the UK with 26% being diagnosed after 24 hours of age and 15.4% diagnosed between 3 days and 6 months of age (CRANE Report 2024).

Objectives: In 2019 the Oxford cleft clinic had an influx of children with delayed diagnosis of overt cleft palates (CP) and submucous cleft palates (SMCP). The team were alarmed that some had been seen in early infancy by tongue-tie practitioners who did not consider palatal anomalies despite being referred to them with feeding difficulties or refer on after no improvement post division.

Methods: Investigative work with regards to establishing the tongue-tie practitioners (TTPs) neonatal examination technique began in March 2020 at the Association of Tongue-tie Practitioners (ATP) AGM. It was ascertained that neonatal palate examination was not part of the TTPs routine initial assessment, they rather concentrated on the tongue base and frenulum. Further education in March 2023 at the ATP annual conference included diagnosis of CP & SMCP, emphasising the importance of and demonstrating direct visualisation of the palate as per RCPCH guidelines published in 2014.

In April 2023, the Cleft Nurses CEN Innovation, Development and Evidence-Based Practice group was initiated as a sub group of the main CEN. It was agreed collaborative working of this new group would further develop the preliminary work with TTPs, into a national teaching tool for all professionals involved with infant feeding in the hope of reducing delayed diagnosis of cleft palate.

Outcome: The Cleft Palate Identification poster was launched in April 2024 by all UK cleft teams with the aim that it is disseminated around maternity, neonatal and paediatric units as well as primary health care teams including TTPs, to educate and inform all clinical staff carrying out initial examinations and those involved with infant feeding.

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Cocaine induced trauma –How is this client group managed by the cleft service?

Mrs Joanna Waldron[1], Mr Alistair Cobb[1], Mr Shaheel Chummun[1]
[1]South West Cleft Service, Bristol, UK

Introduction : The South West cleft service has reported an increase in referrals for patients presenting with cocaine-induced trauma to the nose, lip, and palate. This rise in cases comes in the context of Bristol being recognized in the media as the new "Cocaine capital of Europe."

Aims & Objectives: The goal is to address the impact that this specific cohort of patients has on commissioning, governance, and resources. They represent another group of “non-cleft VPD” referrals who have other significant comorbidities and needs of an extended team, in addition to their oro-nasal and speech reconstruction. The objective is to work together with adjacent specialties as a multi-disciplinary team to create a tailored service specifically designed for this non-cleft patient group. By focusing on these patients, the aim is to improve management planning, resource allocation, ensure proper governance, and enhance commissioning processes, ultimately leading to the development of a more effective and personalised healthcare service.

Method: The discussion will focus on two clinical cases, highlighting a multidisciplinary approach to patient care. This will involve integrating MDT work up and consideration of options for care. The role of surgery and the significant role of speech and language therapy and psychology will be discussed as well as the importance of other specialties.

Result/Conclusion: A multidisciplinary management protocol, pathway, and guidelines are necessary for effectively caring for this client group 1,2. Velopharyngeal insufficiency assessment as well as management and surgical reconstruction should be handled by specialised cleft teams. It is crucial for the commissioning and recognition of this client group to be well-established. The discussion emphasises the importance of determining which patient groups are treated at regional cleft centres, which could shape future clinical practices in the UK.

References
1(Andrews et al, 2024, 2(Pendolino et al, 2023)

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Using Dermal Filler in NHS Patients with Cleft – A Survey of UK Cleft Surgeons

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Background: The judicious use of dermal filler has a role to play in the secondary cleft treatment armamentarium and is the most common enquiry of Adult Returners to CLAPA. Concerningly, the use of dermal fillers within the UK is completely unregulated. Provision of such a service, however, is not standard within UK cleft healthcare. We therefore sought to survey UK cleft surgeons to understand better how to integrate the use of dermal filler into cleft services.

Aim: To explore the opinion of UK Cleft Surgeons on the role and provision of dermal filler to patients with a cleft lip

Methods: Live online survey with immediate post-hoc discussion of results
All UK Cleft Surgeons attending the annual CFSGBI 2024 conference
12 questions explored opinions in the following 3 key themes:
1. Role of dermal fillers in adult cleft lip treatment (perceived vs. actual)
2. NHS provision of dermal fillers to adult patients born with a cleft lip
3. Guidance & Governance on Dermal Filler Provision in Cleft Lip Treatment

Results / Conclusion: A total of 36 out of a possible 57 Cleft Surgeons were surveyed. Although 85% of those surveyed had administered – or wanted to administer – dermal filler in their Cleft Service, only 13% of respondents were part of a dedicated service for doing so. 89% of respondents stated that dermal filler for treatment in cleft lip should be available on the NHS with 53% stating that it should be administered by Cleft Surgeons only. 94% of respondents considered involvement of the Cleft MDT an essential pre-requisite for filler recommendation involving, at the very least, appropriate expert-informed counselling and advice. Dermal filler is already part of the Cleft lip treatment armamentarium and, as such, provision should be standardized within the NHS as part of a Cleft MDT approach.

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Optimal age to assess patients on Alveolar Bone Graft Clinics: a service evaluation

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[1]Newcastle Dental Hospital, Newcastle upon Tyne, UK

Background: Timely assessment of patients with cleft lip and/or palate (CLP) is essential. NHS England[1] states; *'all clefts involving the alveolus will be assessed before the age of 9",* with a dashboard target that 100% of patients are assessed at the right time for alveolar bone graft (ABG)[2].
Since 2020, the Newcastle site of N&Y service has adopted two service pathways for the patient age at the time of assessment on the ABG clinic: either in the 7th year-of-life (between 2020-2022) or 8th year-of-life (between 2023-2024)

Aim: This service evaluation aims to compare the two local care pathways to identify any barriers to care that are associated with patient age at the time of assessment on the ABG clinic.

Objectives:
1. To investigate whether patients attended at the appropriate dental age for ABG, determined by canine root development
2. To investigate the outcome of the ABG clinic
3. To investigate radiation exposure at recall appointments

Methods: Patients were identified from the Northern and Yorkshire (Newcastle site) Regional CLP service database that are diagnosed with cleft lip, cleft lip and palate, cleft lip and alveolus, to ensure that all potential clefts of the alveolus were included. However, a confirmed cleft lip only diagnosis was excluded from further data collection. Data was collected from electronic patient records (Powerchart® and SchApt App®) for patients who received an ABG clinic appointment, between January 2020-December 2024.

Results: In total, 117 patients were analysed: 55 in the 7th year-of-life and 62 in the 8th year-of-life. The principal outcomes were, in order, early canine root development, 1-year review, listed for ABG and orthodontic expansion. Patients assessed in the 8th year-of-life had fewer subsequent appointments and radiation exposures (appointments=90; radiographs=46) than those assessed in the 7th year-of-life (appointments=165; radiographs=64), prior to their alveolar bone graft

References
1NHS England, 2013
2The NHS England Cleft Lip and/or Palate Quality Dashboard, 2016-2017

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What do cleft service users want to know about a potential new surgeon?

Dr Aimee Pudduck[1], Mrs Debra Necrews-Davies[1], Ms Sharnie Dunstall[1]
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Introduction: This will outline the process of involving service users in the recruitment process for a new cleft surgeon.

Aims: To ensure that cleft service user voices were equally represented alongside those of stakeholders and cleft staff in the recruitment process for our new Cleft Surgeon.

Method: A range of Welsh Centre for Cleft Lip and Palate stakeholders, staff and service users were asked what questions they would like to ask a potential new surgeon at interview. From this, general themes emerged and composite questions were developed, which aligned to health board values. Stakeholders and service user representatives were then invited to take part in an interview group panel event.

Results: These questions were asked of all candidates at interview by staff and service users themselves. All candidates responded well to this and fed back that they valued this approach. This approach helped demonstrated how candidates viewed and worked collaboratively with other cleft disciplines, as well as how they engaged with service users. Service users reported feeing valued, engaged and respected in the process.

Conclusion: This highlighted the value and importance of having the service user voice alongside those of other stakeholders and staff in the recruitment process. Service users are now regularly used in the recruitment of new cleft team staff.

Standardisation of intra-operative imaging during cleft surgery: An opportunity for an addendum to national guidance?

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[1]Morriston Hospital, Swansea, Wales

Background/ Introduction: The Institute of Medical Illustrators (IMI) guidance published in 2018 describes core 28tandardizat views for 2D medical photographs at cleft audit. Photographs are an important part of documenting the surgical reconstruction of orofacial clefts, yet the IMI guidance does not incorporate intra-operative images. Without 28tandardization, it is difficult for surgeons to draw comparisons between their own cases, or to compare surgical practice with other surgeons.

Aims & Objectives: The aim is to create a local standard for intra-operative views for primary surgical reconstructions of the cleft lip, palate and alveolus with a view to assessing the appetite for adopting into national guidance.

Methods: A consecutive review of primary cleft surgical reconstructions in a single-surgeon service between September-December 2024. 2D medical images taken by Medical Photographers intra-operatively were analysed collaboratively by the surgical and imaging teams for their view and magnifications. A standard was created to indicate which views and magnification were desired for each respective operation.

Results /Conclusions: 21 primary reconstructions were included (Lip n=6, Palate n=6, ABG n=9). For lip reconstructions, views included anterior/posterior and wormseye at the start, after marking and at the end of the case. For palate reconstructions, views included the hard palate anteriorly (with a mirror) and the soft palate posteriorly at the start and end of the case. Additional images were recorded with the operating microscope when the velar musculature had been dissected and retro-positioned. Alveolar bone graft views included oblique buccal sulcus and anterior hard palate at the start and end of the case. There was inconsistency in magnification used but 1:4 was judged to be the most useful.

In our 28tandardiza cleft services, there is a need for intra-operative image 28tandardization to drive open dialogue and improvement of surgical protocols and outcomes.

Alveolar Bone Graft Pain Management: Optimisation for Day Case Surgery

Ms Sarah-Jayne Edmondson[1], Mr Theodore Pezas[1], Mr David Grimes[1]
[1]Guy's and St Thomas' NHS Foundation Trust, London, UK

Background/Introduction: Patients undergoing alveolar bone grafting (ABG) within our service have traditionally received patient-controlled analgesia (PCA) post-operatively necessitating an inpatient stay.

Aims & Objectives: To assess current pain management of patients in the Evelina London Cleft Service undergoing ABG in order to optimise analgesic prescription perioperatively and assess the feasibility of ABG being performed as a day case surgical procedure.

Methods: Pain management practice in ABG cases in our unit was audited (first cycle 01/04/2019-31/03/2020, second cycle 29/04/2021-15/07/2023). Data collection included baseline demographics, and pain relief methods used intra- and post-operatively including local anaesthetic at both donor and graft recipient sites. Outcome measures evaluated post-operative pain scores and time to mobilisation, first feed and discharge. Use of PCA was discontinued for the second cycle.

Results: During the first cycle, 45 patients (average age: 9 years 4 months; sex: 29 males, 16 females) had a traditional analgesic protocol which included local anaesthesia intra-operatively and a PCA (rates varying from 4-20 mcg/kg/hr with a median of 3 PCA boluses used post-operatively until 0600 the next day). All patients also received regular standard weight-dependent doses of paracetamol (15mg/kg/6hr) and ibuprofen (5mg/kg/6hr) and breakthrough oramorph as required. In the second cycle, 25 patients (average age: 9 years 8 months; sex: 15 males, 10 females) had an analgesic protocol which did not include the use of a PCA. There was no significant change in time to mobilisation, first feed or discharge.

Conclusions: This audit demonstrates that adequate pain management is possible in paediatric ABG cases without the use of a PCA. Sufficient intra-operative local anaesthesia appears to give appropriate pain control to allow early mobilisation, return to oral intake and same-day discharge in certain patients indicating the potential for offering ABG surgery safely as a day-case procedure in appropriately selected patients.

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Velopharyngeal/Palatal Investigation (VPI/PIC) Clinics- An overview of UK Cleft Services

Miss Hannah Chandler[1], Carrie Luscombe
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Background:The 2013 NHS Standard Contract for Cleft Lip and Palate Services states that the cleft pathway must include “nasendoscopy and videofluoroscopy for speech problems if necessary and this may be required at any stage in the care pathway”[1]. These are known as Velopharyngeal Investigation(VPI) or Palate Investigation Clinics(PIC). Long waiting times for these investigations at Cleft.NET.East necessitated exploring different models of service delivery across the UK cleft services, to begin to address the issue.

Objectives:To understand the variation in how UK cleft services deliver this specialist clinic, a survey was sent to all Lead Speech and Language Therapist’s (SLT). The survey was completed by all UK services, sixteen responses including twin site centres were collected. Results were analysed and presented at the Lead SLT cleft forum. Feedback was received and the survey amended.

Methods: Data collected included information on waiting times, clinic organisation, imaging, decision making and staffing.

Results: There is significant variation between centres with waiting times for PIC/VPI ranging from 0-2 months, to 11+ months. In some areas Videofluroscopy was undertaken by SLT only and in others by surgeons and SLTs. Psychology involvement varied from routine involvement, to onward referral if required. Over half of centres completed assessment and decisions in one day however five offered separate appointments. Of six centres with the shortest waiting times for investigations three delivered clinics as a complete assessment and decision in one all day, and three deliver multiple appointments on different days. However importantly for patients, time from referral to decision was shortest in the three centres who did an all-day assessment and decision clinic. All, except one surgeon in one center, have stopped routinely re-imaging post operatively.

Conclusions: This appraisal of UK VPI/PIC delivery, will be used for benchmarking, service improvement and influencing best practice for the future.

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Poster Presentations

Expression of the Shh co-receptors Gas1, Cdo and Boc in mammalian tongue development

Miss Mays Alashqar[1], Dr Maisa Seppala[2], Prof Martyn Cobourne[3]
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Background: The tongue co-ordinates various essential orofacial functions such as chewing, swallowing, guiding food toward the throat and speech articulation. Shh is a signalling molecule that plays a vital role in cranial neural crest cell (CNCC) migration to branchial arches, facial midline patterning, regulation of tongue myogenesis as well as arrangement of the tongue muscles and tendons. However, the precise molecular mechanism by which Shh signalling governs tongue myoblast migration and tendon development remains elusive.

Aims & Objectives: This study aimed to further investigated the role of Shh signalling pathway in tongue formation by examining its co-receptors', Gas1, Boc and Cdo, expressions during tongue formation (mouse embryonic days 11.5 to 15.5) and their possible functions by investigating mouse knockout phenotypes of single and compound mutants of Gas1, Boc and Cdo.

Methods: Gas1, Boc, Cdo, Shh and Ptch1 mRNA expressions were studied by carrying out radioactive in situ hybridisation. Mutant tongue phenotypes of Gas1-/-, Boc-/-, Cdo-/-, Gas-/-;Boc-/-, Gas-/-;Cdo+/- and Gas1-/-;Shh+/- were analysed using haematoxylin and eosin stained anterior, middle, and posterior sections of the tongue.

Results/Conclusions: Gas1, Boc and Cdo are strongly expressed throughout the tongue development and their mutant phenotypes are indicative of possible overlapping roles during tongue development in tongue myogenesis and tendon formation. While single mutant mice demonstrated no remarkable gross anomalies, double knockout mutant mice exhibited multiple abnormal tongue phenotypes such as bifid tongue, disrupted intrinsic muscle patterning, tendon formation and tongue outline especially affecting the first branchial arch derived anterior part of the tongue. These finding suggest that Shh co-receptors play an important role facilitating Shh function during tongue development and can provide further understanding of the craniofacial manifestations of the SHH signalling-associated congenital craniofacial conditions such as ciliopathies.

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A national survey of radiographic imaging protocols and CBCT usage in Alveolar Bone Grafting treatment

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Background: Alveolar Bone Grafting (ABG) is a critical procedure that Cleft Lip and Palate patients undergo, as it addresses the alveolar bone deficiency within the maxilla that results from the cleft (Bergland et al., 1986). There are currently no standardised guidelines regarding radiographic imaging for patients undergoing ABG. The availability of Cone Beam Computed Tomography (CBCT) may yield additional diagnostic information in comparison to two-dimensional radiography in ABG treatment, however its use must be balanced against the higher effective dose to the patient (Isaacson et al., 2015).

Aims & Objectives: To ascertain the radiographic imaging protocols of cleft centres across the UK and identify how CBCT is used in relation to ABG treatment.

Methods: An online survey was disseminated to members of the Cleft and Craniofacial Society who deliver cleft care in the UK and Ireland.

Results/Conclusions: A dental panoramic tomograph and upper occlusal were the radiograph of choice pre-ABG in most cases (89.7-93.1% and 69% respectively), whereas an upper occlusal was taken post-operatively (82.8%). All post-operative imaging was taken between 3-9 months. Most clinicians (86.2%) use the Kindelan-bone fill index to assess graft success. There was little difference in prescribed imaging between uni- and bi-lateral cleft lip and palate cases. There was no routine use of CBCT pre- or post-operatively. Common indications of CBCT were the presence of supernumerary teeth and ectopic maxillary canines, and clinical signs of graft failure. Consent for CBCT scanning was most often obtained by the requesting clinician (44.8%), and reporting undertaken by the dental & maxillofacial radiologist (34.5%). There was variation in clinical knowledge of effective dose and cancer risk in relation to CBCT. In conclusion, two-dimensional radiographic assessment continues to be used routinely pre- and post-ABG, with CBCT only used in select cases to yield additional diagnostic information, which follows UK radiology guidelines.

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A Case-report of Bilateral Facial Cleft with Cleft Lip and Palate and Surgical Management

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Introduction: Craniofacial clefts are rare anomalies and surgical management can be challenging due to lack of experience, even more if multiple anomalies coexist.

Aims & Objective: We present a rare and complex case of a female patient born with bilateral facial clefts (complete right Tessier number 4, partial left Tessier number 5) and left-sided unilateral cleft lip and bilateral cleft palate. She had bilateral lower lid colobomas with a severely malformed right eye with no apparent vision but a normal formed left eye.

Methods: Description of a case report from patient notes. A literature search on PubMed Medline was performed.

Results/Conclusion: The treatment planning and sequence of `intervention were laid out after discussion among cleft surgeons. Treatment goals were: (1) address immediate functional problems; restore eyelid anatomy to preserve the globe right eye and prevent visual loss left eye, allow adequate oral intake and (2) restore facial anatomy and appearance.

The child was surgically treated by the cleft team and ophthalmology. Surgical sequence was as follow. At the age of 4 months, the right facial cleft was repaired and the right lower lid coloboma remodelled using a Hughes flap and with separation of adhesions from the lid to the globe. At 6 months, the unilateral cleft lip was repaired and a vomer flap was performed, the Hughes flap was divided and a Tenzel flap created for further right eyelid repair. At 10 months, bilateral cleft palate repair was performed. At 19 months, revision of right facial cleft and repair of left facial cleft and release of ankyloblepharon.

Unlike cleft lip and palate, management of facial clefts is not standardised and sequencing and timing of surgery not well established. There is uncertainty of what is the most appropriate management to result in optimal functional and aesthetic outcome.

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Rates of Canine Impaction in Cleft Lip and/or Palate Patients in North East of England

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Background: Clefts involving the alveolus can result in ectopic or impacted teeth due to a lack of bone for eruption1. Placement of an alveolar bone graft can provide bone into which previously ectopic teeth can erupt. A high incidence of impacted canines has been reported in the literature for patients with a cleft, between 12% and 35% greater compared to patients without a cleft2, 3, and 4. Alveolar bone grafting is generally performed before eruption of the cleft-side canine, usually when the root is half to two-thirds developed to encourage eruption through the graft5.

Aim: To identify patients who had previously had an ABG and subsequently developed an impacted canine requiring exposure (either open or closed) or extraction.

Standards: There is no national target for impacted canines in patients with a cleft who have had a bone graft. The published data suggest a variable impaction rate. The last data collection cycle showed an impacted canine rate of 3%.

Methodology: All patients who had received a bone graft since the last data collection cycle (2018) until present were included. Patients aged 12 years of age and under were subsequently excluded, as the canine was not expected to be erupted. Patients undergoing oral surgery procedures were identified from correspondence and case notes. Data were collected using a standard proforma and analysed using Microsoft Excel.

Results: 235 met criteria for inclusion. There were 20 impacted canines identified giving a canine impaction rate of 8.5%. Of the 20 impacted canines, 13 patients had pre ABG expansion. Of the patients with impacted canines, 16 were in unilateral cleft patients and 4 bilateral.

Conclusion: Findings were disseminated among the cleft team within the NHNFT service that canine impaction rates have increased since data was last collected, but is still below that quoted in the literature.Data collection is ongoing.

References:

1. McIntyre GT. Management of patients with non-syndromic clefts of the lip and/or palate part 3: from age 10 until adulthood. 2014; 41: 876-881
2. Semb, G., Schwartz, O., Andreasen, J. O. (Ed.), Petersen, J. K. (Ed.), & Laskin, D. M. (Ed.) (1997). The impacted tooth in patients with alveolar clefts. In Textbook and color atlas of tooth impaction. (pp. 332-348). Copenhagen: Munksgaard.. Publication link: 43bafe18-df6c-4c28-a0eb-d8416e6ccaaf
3. Enemark H, Jensen J, Bosch C. Mandibular bone graft material for reconstruction of alveolar cleft defects: long-term results. Cleft Palate Craniofac J. 2001 Mar;38(2):155-63
4. Oberoi et al. Three-dimensional assessment of the eruption path of the canine in individuals with bone-grafted alveolar clefts using cone beam computed tomography.Cleft Palate Craniofac J. 2010 Sep;47(5):507-12
5. Bergland O et al. Secondary bone grafting and orthodontic treatment in patients with bilateral complete clefts of the lip and palate. Ann Plast Surg. 1986 Dec;17(6):460-74

Van der Woude in unilateral cleft lip: phenotypic patterns and surgical adaptations

William Breakey[1], Matthew Fell[2], Jonathan Burge[1], David Sainsbury[3], Daniela Tanikawa[4], Amy Davies[5], David Chong[1]
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Background: Van der Woude syndrome is synonymous with a severe phenotypic expression of cleft lip and palate. Traditionally the severity of unilateral cleft lip has been associated to the width of a cleft. We examine the presentation of the unilateral cleft lip in Van der Woude syndrome, with a focus on the lateral lip element.
Aims: To further examine and better understand the role of hypoplasia in unilateral cleft lip and palate.

Methods: This is a retrospective, observational study of patients with a unilateral cleft lip and palate, a diagnosis of Van der Woude syndrome and pre-operative clinical images treated at The Royal Children's Hospital, Melbourne, Australia; Royal Victoria Infirmary, Newcastle upon Tyne, UK or Menino Jesus Municipal Hospital, São Paulo, Brazil. Patient images were classified into different levels of lateral element hypoplasia according to the Melbourne Classification.

Results: Eight patients with Van der Woude syndrome and unilateral cleft lip and palate were identified across the three hospital sites. All eight patients had left sided unilateral cleft lip and palate and Melbourne Classification Type 2 tissue hypoplasia, with shortened vertical lip and red vermillion height.

Conclusions: This cohort of children with unilateral cleft lip and palate in the setting of Van der Woude syndrome presented with a left sided preponderance and Type 2 hypoplasia of the lateral lip element. It is important to observe the presence of hypoplasia in the lateral lip element when attempting to balance any cleft lip repair. Technical nuances are presented which may assist in improving appearance outcomes.

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Empowering our Community: CLAPA's Move into Campaigning

Mr Lachlan Bruce[1]
[1]Clapa

Background/Introduction: CLAPA, the national charity for cleft lip and palate, has long provided direct support to individuals and families affected by cleft conditions. But recognising the need to address the systemic challenges facing our community, CLAPA is developing its first dedicated policy and campaigns strategy. This marks a shift, positioning the organisation to influence formally national policies and improve outcomes for those with cleft lip and palate.

Aims & Objectives:

- Represent the lived experiences of people with cleft conditions in policymaking.
- Advocate for better, equitable access to cleft care and services across the UK.
- Collaborate with policymakers, healthcare professionals, and the cleft community to raise awareness of cleft.

Methods: This initiative is in its early stages, with CLAPA appointing a Policy and Campaigns Manager to lead the work. Early efforts include gathering insights from the cleft community and establishing foundational relationships with policymakers and healthcare leaders. Future plans will involve developing campaigns and engaging decision-makers to influence cleft care services.

Results/Conclusions: As this work begins, outcomes currently focus on building capacity and laying the groundwork for future impact. Success in the future will be measured by the quality of data gathered and shared with decision makers, community engagement levels in our campaigns, and the positive change achieved on behalf of our community.

CLAPA's shift into campaigning reflects a long-term commitment to advocating for systemic change and improving patient experience through policy influence.

References:

- Annual Supporter Survey 2023
- Annual Supporter Survey 2022
- Cleft Development Group Patient Engagement Summary
- CLAPA Clinician Survey Report 2023
- Advocacy inquiries to CLAPA (2021–2024)
- CLAPA Communications Team Survey (Summer 2024)

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Impact of ABG clinics on patient pathways; 10 year retrospective review of a regional service.

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Background: The Newcastle hub of the Northern and Yorkshire Cleft Lip and Palate service introduced a designated alveolar done graft (ABG) clinic in 2020 which is held at the hub site for the service. This is in contrast to previously seeing patients requiring ABG assessment within both hub and spoke multi-disciplinary clinics followed by collection of radiographs and records by orthodontic colleagues at spoke sites since the establishment of the service in 2002.

Aim: To review whether running a dedicated clinic was providing improved patient care for those requiring assessment and/or management of alveolar defects.

Methods: Retrospective review of demographic data and pathways for patients undergoing ABG surgery between January 2015 and December 2024 at the Newcastle hub of the Northern and Yorkshire Cleft Lip and Palate service was undertaken. Patients undergoing repeat ABG surgery were excluded from the review as such pathways would vary from protocol.

Results/Conclusions: 191 patients underwent first ABG procedures between January 2015 and December 2024 at the Newcastle site. Mean age of patients undergoing surgery varied by year throughout the time period with a tendency towards surgery at a younger age following introduction of the ABG clinic. Staff feedback was obtained from team members involved in the ABG clinic to assess their views on the effectiveness of the clinic.

Patient pathways have been streamlined since the introduction of ABG clinics within the regional service as evidenced by the mean age at which surgery was completed over the decade. Staff feedback was positive particularly regarding the improved patient journey.

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Psychological Input During Routine MDT Appointments at The Evelina London Cleft Service

Dr Hollie Clark[1], Miss Ayomide Adetosoye[1,2], **Dr Kate Le Marechal**[1]
[1]Guy's and St Thomas' NHS Foundation Trust, London, UK, [2]Loughborough University, Loughborough, UK

Introduction: Clinical psychologists support the wellbeing of patients with cleft lip and/or palate and their families by providing direct care and collaborating with multidisciplinary teams (MDT) (Stock et al., 2020). The Evelina London Cleft Service has a clinical psychologist present at all MDT appointments, with involvement dependent on patient need. The Tiers of Involvement Measure (TIM), introduced by the Cleft Clinical Psychology Clinical Excellence Network (CEN), measures psychologist involvement in Cleft MDT appointments (Fitzsimons et al., 2024). UK-based cleft psychology teams submit TIM scores annually to the Cleft Registry and Audit Network however, no site-specific investigation has been conducted to investigate whether there is a significant difference between TIM scores at age 5/10/15 for young people under the care of the Evelina Cleft Service.

Aims & Objectives: The objective of this review is to assess whether there is a significant difference in psychological involvement for patients attending MDT appointments at age 5/10/15 in the Evelina London Cleft Service. This will evaluate whether psychological need within clinical appointments varies across different stages of routine care.

Methods: A Chi-squared test will be used to assess whether category counts differ across three time points (age 5/10/15). The four categories include; Tier 0 (patient not seen by psychologist), Tier 1 (psychological input not needed), Tier 2 (psychological input provided during clinic) and Tier 3 (further action required e.g., liaison with external agencies and/or further psychological input). Observed frequencies will be compared in a contingency table, assessing category distribution over time.
Results /Conclusions: The results will assess psychology contribution to MDT appointments, highlighting potential variations in psychological needs across different ages. Findings will evaluate the use of psychological resource in MDT appointments and may also warrant further research to guide the development of targeted resources, or clinical interventions at key stages of care.

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Self-esteem Webinar: a new approach to mental health at CLAPA

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Background: Research has identified that adults born with a cleft may experience concerns regarding mental health and overall quality of life. This includes low self-esteem and self-confidence, as well as feelings of low self-worth (Ardouin et al., 2020; Ardouin et al., 2021). At CLAPA, one the most popular episodes of all time on our Cleft Talk Podcast was on the topic of self-esteem.

Aims and Objectives: To provide an accessible lasting resource for adults born with a cleft on the topic of self-esteem. To improve the mental health and wellbeing of adults born with a cleft.

Methods: Through collaboration with the NHS Cleft Team Clinical Psychologists, members of our community and existing psychological resources such as FaceIT, we developed an evidence based webinar. This provided psychoeducation, an introduction to psychological theories and techniques to improve self-esteem. With a live audience of 10 attendees, and hosted by NHS professionals, a CLAPA volunteer and CLAPA staff member, this was recorded and is an easily accessed resource on the CLAPA website.

Reports/conclusions: Of those who have viewed the webinar, feedback has been overall very positive with 80% feeling better informed about the topic and feeling more confident about addressing cleft related issues in their own life. This has had over 100 views since publication (16th Sept) and continues to be utilised.

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Making sense of speech intelligibility outcome data: Findings from the Cleft Collective

Miss Amy Davies[1,2], Distinguished Prof Sharynne McLeod[3], **Prof Yvonne Wren**[1,2,4,5]
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Introduction: Speech intelligibility is a concern in children born with cleft palate, with nearly 20% of 5-year-old children being barely intelligible.[1] The Intelligibility in Context Scale (ICS), a 7-item parent-report tool, is recommended in the International Consortium of Health Outcome Measures (ICHOM) standard set for cleft lip and/or palate (CL/P).[2] The ICS measures intelligibility by assessing how well a child is understood by various communication partners, with higher scores representing better intelligibility.[3],[4] The inclusion of the ICS in ICHOM is valuable due to its ease of use and versatility; however, while normative data for the general population is emerging globally, reference data for children born with CL/P does not yet exist, making comparisons challenging.

Aim: Report reference data on the ICS for 5-year-old children born with CL/P.

Methods: Parental questionnaire data from the Cleft Collective were used.[5] Descriptive statistics of ICS scores for the total sample and stratified by cleft type were performed. Differences in ICS scores were evaluated using Kruskal-Wallis tests with Dunn's post hoc tests and Mann-Whitney U tests for syndromic versus non-syndromic clefts, with reference ranges calculated for these groups.

Results/conclusion: Data were available for 687 5-year-old children. Median scores for children with cleft lip only were higher (5.00, 95%CI 5.00–5.00) than those with any form of cleft palate (4.14, 95%CI 4.14–4.29); cleft lip scores aligned with normative data. Children born with cleft palate and a syndrome scored lower than those born with a cleft palate without a syndrome. Among 496 children, where data were also available at age 3, 85% improved, 6% remained the same, and 9% scored lower at age five. Data are now available for comparison with individual children in clinical settings.

1. Sell et al.(2015); 2. Allori et al.(2017); 3. McLeod et al.(2012); 4. McLeod et al.(2020); 5. Davies et al.(2024)

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Creating a Multilingual Case History Form for Speech and Language Therapy in Cleft Care

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[1]NWNW and IoM Cleft Network, Manchester, UK, [2]NWNW & IoM Cleft Network, Liverpool, UK

Background: Speech and language therapists (SLTs) working in cleft care increasingly encounter multilingual families whose linguistic and cultural contexts are critical for effective intervention [1]. Traditional case history forms often lack the nuance required to capture multilingual dynamics, including language exposure, proficiency, and cultural considerations [2]. To address this gap, a new multilingual case history form was developed to support SLTs in gathering detailed and relevant information, ensuring inclusive and culturally appropriate care.

Objectives: The study aimed to design, implement, and evaluate a new case history form tailored to multilingual families accessing cleft services. The primary objectives were to:
1. Enhance the understanding of multilingual language use within families.
2. Provide SLTs with a structured yet flexible tool for case history taking.
3. Ensure the form aligns with time constraints and clinical needs.

Methods: The form was devised through a participatory approach, incorporating feedback from SLTs working with multilingual families in cleft. It includes sections on background information related to language, family language preferences, education, and child's speech, language and communication. The form was trialed with 11 SLT's across the NWNW IoM Network and evaluated through questionnaire.

Results/Conclusions: Preliminary findings indicate that the form significantly improves the collection of language and cultural information. SLTs reported increased confidence in addressing multilingualism and better understanding of family communication patterns.
The multilingual case history form represents a valuable tool for cleft care, promoting equity and inclusivity. Future work will focus on refining the form based on feedback and sharing of the case history form with other cleft centres.

References

1. Pert, S. (2022).
2. Royal College of Speech and Language Therapists. (2025).

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Photography Exhibition: What Young People with CL/P Want Others to Know About Their Lives

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Background: Young people (YP) with CL/P have unique life experiences, however very little research has explicitly focused on YPs experiences, voices, wants and needs [1, 2]. It is only possible to change practices and improve lives if we understand the perspectives of YP with CL/P. One approach to achieving this is through photovoice, which is an effective participatory method for communities to illustrate their strengths and needs through images and stories of everyday life, to promote critical dialogue and bring about change [3].

Aims & Objectives: This project aimed to better understand YP with CL/Ps life experiences and support YP with CL/P to feel empowered. YP participated as co-researchers and actively contributed to developing the research questions which were 1) What has having a cleft meant for YP in their lives? 2) What do young people want clinicians to know about their cleft journey?

Method: Participatory action research approaches [4] were used to engage YP with C/LP as co-researchers. The YP completed a PhotoVoice [3] project and collected 145 images with short paragraphs explaining each image and how it addressed the research question(s). The YP then collaboratively analysed the data during a creative participatory workshop to produce themes illustrating their experiences.

Results/Conclusions: The YP developed six themes: 1) memories, 2) relationships/journey, 3) treatment and thoughts and feelings, 4) change, 5) perspective and 6) opportunities and awareness. This exhibition illustrates the work of the YP through displaying example images from each theme and detailing the stories they represent. Immersion in this exhibition will leave viewers with a better understanding of the stories and lives of YP with CL/P.

References

1. Sharif MO, Callery P, Tierney S (2013).
2. Davies J, Davidson E, Harding S, Wren Y, Southby L (2025)
3. Wang C, Burris MA (1997).
4. Kemmis S, McTaggart R (2005).

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Use of COM-B with a CNS team to address barriers to providing oral health advice.

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[1]NWNW and IoM Cleft Network, Manchester, UK

Background: Good oral health is vital for children with cleft lip and/or palate (CLP), as their care may be compromised by dental disease [1]. Audit data from Manchester revealed only 58% of 5-year-olds born in 2016 were dentally fit. Studies highlight the need for targeted preventative programs for parents and children with CLP [2]. The Clinical Nurse Specialist (CNS) team, who provide intensive care during the child's first year, are well-placed to deliver oral health advice. The COM-B model [3,4] (Capability, Opportunity, Motivation, and Behaviour), was used as a framework to identify possible barriers that may affect oral health promotion at the weaning visit.

Aims: To recognise barriers faced by the CNS team when providing oral health advice and develop appropriate teaching aids for use during CNS visits.

Methods: A COM-B questionnaire was administered to the CNS team to assess barriers to providing consistent oral health advice. The evaluation was conducted by a trainee health psychologist.

Results/Conclusions: Six CNS team members completed the questionnaire. Results identified that while the team was motivated to provide oral health advice, they lacked sufficient resources and standardised information. In response, an existing aide-memoire was modified to include relevant information, and advice videos were created and linked to QR codes in an oral health leaflet for parents.

The updated aide-memoire and advice videos aim to standardise oral health advice during weaning visits. The COM-B questionnaire will be re-administered to evaluate the effectiveness of these resources. Delivery of oral health advice will be audited at 18-month clinics, and longer-term data on oral health outcomes at 3 and 5 years will be reviewed.

References
1. Grewcock, R.E., et al (2022).
2. Chapple, J.R., & Nunn, J.H. (2001).
3. Keyworth, C., et al (2020).
4. Michie, S., et al (2011).

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Associations between the timing of primary palate repairs and speech outcomes aged 3.

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A UK NHS England Dashboard key performance indicator (CLP04) requires a primary cleft palate repair to be completed by 13 months of age[1] and is considered an 'optimal' palate repair. A 'delayed' palate repair is completed beyond this 13 month time frame and has been associated with poorer articulation outcomes[2].

Data review showed a number of palate repairs were completed after 13 months at Cleft.NET.East, between 2017-2021. The study aimed to explore associations between speech outcomes aged 3 and timing of palate surgery in patients with all subtypes of cleft palate.

A retrospective case note review was conducted, as part of an internal audit project within Cleft.NET.East and aged 3 clinical assessment speech data as well as the timing of primary palate repair was collated from all non-syndromic patients with a cleft palate (+/- cleft lip) in 5 birth cohorts (between 2017 and 2021). Speech outcomes included resonance, airflow errors and cleft speech characteristics.

An optimally timed palate repair is not always possible for a variety of reasons and understanding the impact of this on speech outcomes for this patient group is important. The findings from this audit will add to the evidence base on this complex national issue, inform care pathways, facilitate best outcomes for patients and could be used for service improvement in the future.

[1] NHS England Specialised Services Quality Dashboards (2022) Women's and Children Specialised Surgery in Children Cleft Lip and / or Palate Services including Non-Cleft Velopharyngeal Dysfunction (VPD) (All Ages).

[2] Shaffer AD, Ford MD, Losee JE, et al. The association between age at palatoplasty and speech and language outcomes in children with cleft palate: an observational chart review study. Cleft Palate Craniofac J 2020;57:148–60.

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A Retrospective Study exploring the need and type of Speech Therapy intervention following 18-month assessment

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Introduction: The national routine cleft care pathway specifies children with a Cleft Palate (CP) should receive a Speech and Language Therapy (SALT) review between 18-24 months of age post-palate repair. This review aims to identify children who may have 'at risk' velopharyngeal function early, enabling timely therapeutic and/or surgical intervention. However, there appears to be a notable increase in the number of children who are presenting with delayed language and communication skills at their 18 month review. They require intervention to develop these skills which in turn supports the differential diagnosis of Velopharyngeal Incompetence (VPI). This study investigates the proportion of children requiring additional intervention and types of intervention provided, with the goal of informing the revision of the Early Years Pathway.

Aims:

- To determine the number of children who required follow-up intervention after their 18 month assessment, before their 3 year review.
- Identify types of intervention offered

Method: A retrospective study was conducted to analyse the data of 50 children born with a CP, UCLP or SMCP who were treated between February 2019 and October 2019.
Results:
Preliminary findings indicate that 87% seen at 18 months required additional intervention. The distribution was as follows:

- 44 % of children - review in 3-6 months by Specialist Cleft SALT
- 1% of children - review in 12 months by Specialist Cleft SALT
- 4% of children - 1:1 intervention from Specialist Cleft SALT
- 51% of children - referred to the local Speech and Language Therapy service

Conclusions: This study highlights the need for timely intervention for children both pre-and post 18 month assessment. Early intervention facilitates language development, improves differential diagnosis for VPI and may reduce the need for more intensive interventions at later stages. These findings will inform the revision of the SALT Early Years Pathway.

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Cleft++ mentoring service for young people

Mrs Claire Evans[1], Nicky Fawcett[1]
[1]Cleft Lip and Palate Association

Background: Research suggests that young people born with a cleft may experience bullying and develop low self-esteem. CLAPA's Children and Young People's Council and young adults known to CLAPA worked alongside staff to develop Cleft++. A mentoring service to support young people with these and other cleft-related challenges.

Aim: To provide a safe and supportive virtual space for young people to develop coping skills, to better deal with setbacks and challenges related to their cleft; feel listened to and understood; and connect with others born with a cleft.

Method: Cleft++ uses a specialist online messaging platform to safely connect 10-17-year-olds with a trained volunteer mentor who will draw on their cleft-related experiences to offer personalised support. Topics are self-chosen and directed by the mentee over a twelve-week period.

Results: The service has supported 10 young people since its inception in September 2023. Areas of support have included:

- Overcoming worries and anxieties related to Alveolar Bone Graft Surgery
- Moving from primary to secondary school and the worries and anxieties this life transition can create
- Connecting with others born with a cleft to reduce isolation and improve self-view
- Decisions about future surgery
- Help to cope with cleft-related questions, negative comments, and bullying

A mentee told us; 'The support I received in mentoring was incredible! I really appreciated being able to talk to someone who understood what I was going through as I have not always had that opportunity. In the past few months, I have become much more confident when it comes to my cleft and a lot less worried about the future.'

References:

Guillén, A. R., Peñacoba, C., & Romero, M. (2020). Psychological variables in children and adolescents with cleft lip and/or palate. Journal of Clinical Pediatric Dentistry, 44(2), 116-122.

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Protocol for a prospective cohort study of patients with non-cleft velopharyngeal dysfunction

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Background: Velopharyngeal Dysfunction (VPD) describes failure of the soft palate, lateral and posterior pharyngeal walls to separate nasal and oral cavities during speech. Most commonly arising in association with a previously-repaired cleft palate, VPD can also occur with certain syndromes, neurological insults, and surgical interventions; collectively known as non-cleft VPD [1]. Speech surgery for VPD has been reported in patients with a history of cleft palate [2]. However, there is a dearth of evidence to guide treatment of patients with non-cleft VPD. Furthermore, cleft centres are often under-resourced to manage these patients.

Aims & Objectives: The aim is to outline the design and methodology for a cohort study, which will evaluate baseline characteristics, clinical, speech and patient-reported outcomes in patients undergoing treatment for non-cleft VPD.

Methods: This is a prospective cohort study recruiting patients, who are undergoing management for non-cleft VPD, which may consist of surgery, speech and language therapy, or palatal prosthesis devices. Choice of intervention will be selected for each participant by the multidisciplinary cleft team. Outcomes will be reported according to the previously-published core outcome set for velopharyngeal dysfunction (COS-VPD).

Results/Conclusion: The study is underway at the Dublin Cleft Centre and the authors will use this presentation to establish collaboration with other members of the CFSGBI. Pooling of outcomes between centres will provide robust evidence that would inform cleft teams about the management of these complex patients. The study could also serve to quantify the volume of non-cleft VPD cases being managed across the UK and Ireland and this would provide information for service development and resource allocation.

References:

1. Kummer, A.W., et al. Non-cleft causes of velopharyngeal dysfunction: implications for treatment. IntJPediatr Otorhinolaryngol, 2015.
2. de Blacam C, et al. Surgery for Velopharyngeal Dysfunction: A Systematic Review of Interventions and Outcomes. Cleft Palate Craniofac J. 2018

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Exploring children's and young people's experiences of cleft lip and palate services: A qualitative study

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Background: The United Nations Convention on the Rights of the Child (1989) and the UNCRC (Incorporation) (Scotland) Act 2024 call for the inclusion of the child in healthcare decision-making. Despite this, limited research explores the voices of children/young people (YP) with cleft lip and/or palate (CL+-P) about the services they receive (Jensen et al.,2022;Sharif et al.,2013).

Aims/Objectives: This study aimed to explore the views of children/YP with CL+-P regarding cleft-related healthcare experiences in multidisciplinary (MDT) clinics and their ideas for improvement. It also aimed to explore the opinions of professionals within a multidisciplinary cleft-care team regarding the acceptability and practicalities of quality improvements based on the children's/YP's feedback.

Methods: Study 1a: Listening to the children/YP's voices: Qualitative Explorative Study. Two face-to-face focus groups were conducted, one with four children/YP aged 8-10 and one with five children/YP aged 11-14. Data was analysed using Thematic Analysis (TA) informed by a theory of acceptability (Braun & Clarke, 2022). Study 1b: Exploring ideas for change: Qualitative Explorative Study. A second focus group, held online with three children/YP aged 8-14, to gather ideas for improving the MDT clinic. Data was analysed using TA (Braun & Clake, 2022). Study 2.Quality Improvement (QI): A workshop with four members of a cleft MDT was undertaken to explore children/YP's feedback/ideas and to identify practical steps for QI based on their suggestions.

Results/Conclusions: Findings indicated that the children/YP wanted to be involved in their cleft-related healthcare. They demonstrated a desire for autonomy and empowerment within a healthcare system that offered (child) person-centred care. Study 2 found that professionals were willing to accept and implement changes the children/YP proposed related to clinic environment, communication, information, and desired autonomy. The potential barriers to implementing changes included a combination of perceived operational issues, space and human resource aspects, and individuals' acceptance of change.

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Reestablishing a Regional Alveolar Bone Graft (ABG) Clinic in Northern Ireland: A Two-Year Service Evaluation.

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Background: Covid 19 delayed the cleft ABG service with staffing issues compounding it. To ease waiting lists mutual aid was sought.

Aim:
- Assess the quality of ABG outcomes
- Quality assure the service

Objectives: To Assess:
- Number of ABGs surgeries
- ABG outcomes
- Timing of ABG provision regarding canine position and success
- Presence of post operative complications
- Impact of removing presurgical appliances without orthodontic replacement in theatre post-surgery.
- Differences in outcome between unilateral single stage surgery and bilateral grafts that were completed as a single operation

Methods: This was a prospective service evaluation with data compiled for seventy – two successive patients on the Regional Alveolar Bone Graft (ABG) Clinic in Antrim Area Hospital over a two-year period (August 2022 - August 2024). Patients underwent clinical examination six weeks and six months post-operatively. Radiographs were graded six months post-surgery using the Kindelan Index. All surgeries were completed by a single cleft surgeon with outcomes assessed by one different independent operator. Data was anonymized at source and recorded on an excel spreadsheet.

Results: Eighty-five bone grafts were completed with a 100% success rate (i.e Kindelan grade 1 and 2). Thirty-two ABGs were bilateral and fifty-three unilateral surgeries. Forty patients (56%) had presurgical orthodontics. Sixty-seven surgeries (79%) were completed pre canine eruption and eighteen surgeries (21%) were performed post canine eruption. Fourteen granulomas were recorded and resolved within six months without impacting the Kindelan score. The bilateral ABGs grafted as a single procedure were as successful as unilateral ABGs.

Conclusions:

- Removing any orthodontic appliances presurgery without orthodontic archwire replacement in theatre in bilateral cases didn't impact success.
- Over time, less canines were past the ideal root formation stage at surgery. This reflects service improvement with ABGs being provided closer to the ideal patient age.

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Naso-alveolar moulding: a method for pre-surgical management of infants with cleft lip and palate

Miss Aliya Hasan[1], Mr Gavin Power
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Background: Naso-alveolar moulding is a technique used in the pre surgical management of infants born with a cleft lip and palate. In infants born with a unilateral or bilateral cleft lip and palate, there are several reconstructive challenges including a hypoplastic maxilla and a deficient columella. Nasal surgeries can result in a lot of scarring. Naso-alveolar moulding is a technique used to reduce this reconstructive challenge. This technique can permanently modify the cartilage to manage cleft nasal deformities below the age of 6 months old. The procedure has been shown to improve aesthetics of the nose with a reduction in scarring. This technique is used worldwide with the most recent success rate evidenced as 71% in a recent meta-analysis

Aims and Objectives: The aim of this case report is to discuss the advantages of naso-alveolar moulding and demonstrate the significant improvements of this technique.

Methods: The appliance is made of an acrylic moulding plate with a nasal stent in the anterior part of the plate. The plate is adjusted on a weekly basis to correct the nasal asymmetry, improve the form of the alveolus and elongation of the columella.

Conclusion: Naso-alveolar moulding is a technique used across various countries with the main aim of providing less columellar deviation and an aesthetic improvement of the nose in infants prior to surgical repair of a cleft lip and palate. This case report has demonstrated how successful this technique can be and the positive impact it has.

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Caries Experience of Cleft Lip and/or Palate Children: A Qualitative Exploration of Barriers and Motivations

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[1]Zarqa University, Zarqa, Jordan, [2]University of Liverpool, Liverpool, UK, [3]Alder Hey Children's Hospital, Liverpool, UK, [4]Liverpool John Moores University, Liverpool, UK, [5]University of Sheffield, Sheffield, UK

Aims and Objectives:

- To observe changes in the decayed, missing, and filled teeth (DMFT) index over five years.
- To explore barriers and motivators for oral health as perceived by children with CL/P and their carers.
- To understand the impact of caries on children with CL/P and their carers.

Procedures: Nine children, recruited from Alder Hey Children's Hospital, participated in this study, with a mean age of ten years and seven months. DMFT scores were recorded by a calibrated consultant in paediatric dentistry (JM), who previously recorded scores at age five. Semi-structured interviews were conducted with the children and 12 carers, then transcribed, coded, and analysed for themes.

Results: The mean dmft at age five was 1.77, ranging from 0 to five, and the mean DMFT at age 10 was 0.88, ranging from 0 to three. Five main themes emerged: 'Learning the ropes,' 'Out of sight, out of mind,' 'A constant battle,' 'It's all about consistency,' and 'The push they needed,' with several subthemes. Participants discussed caries impacts, oral hygiene challenges, motivators, and education.

The main barriers for children are tiredness, and toothbrushing not being a priority in their busy schedule. The main barriers highlighted by carers are the difficulty to find a GDP, busy schedules, and the difficulty to control unhealthy snacking outside the home environment.

The main motivators for children and carers are acquiring a toothbrushing habit, rewards for brushing the teeth, the use of timers, carers being involved in toothbrushing, and being told that the child has caries.

Conclusions: Ages five to 10 are critical for establishing toothbrushing habits in children with CL/P.

Carers should be empowered to support good toothbrushing habits early to prevent poor practices.

Caries showed minimal impact on daily life and OHRQoL in children with CL/P and their carers.

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Families' perceptions of high intensity speech therapy; A Pilot of articulation group therapy.

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Background: By age 5, 38.8% of children born with a cleft lip and palate (CLP) have not achieved typical speech but those who receive speech therapy have less speech errors (Sell et al, 2017). Research indicates intervention can be more effective when delivered frequently, resulting in improved progress over a shorter period (Alighieri et al., 2021). Group therapy can supplement individual therapy by providing a more natural communication environment in which patients can learn from others present (Farquhar and Hammond, 2022). Is it feasible for families to commit to attending high intensity group speech therapy?

Aim: To explore families' perceptions of high intensity group speech therapy for children born with CLP experiencing cleft speech characteristics.

Method

- Over 2-week period, we delivered 3x 1-hour sessions of group articulation therapy per week
- 8 children attended aged 3 - 11.
- Each session included 2 group therapy activities.

- Sessions were held at Cardiff Metropolitan University (which provided an opportunity for SLT students to observe and participate).
- Feedback was gathered via a questionnaire and a patient picture rating scale.

Results: 63% of questionnaires were returned.

Respondents gave positive feedback, stating their children enjoyed the therapy activities and were motivated to practice their speech in the group setting, and reporting that the session helped increase in their confidence to carry out speech practice with their children.

Respondents reported the group to be an invaluable experience for connecting with others on similar journeys.

Respondents also gave positive feedback regarding duration of sessions, and the venue.

Conclusion: This proved to be a successful pilot. Families were able to commit to high intensity group speech therapy and have requested further sessions.

Future research should include a formal measure of the patient's speech progress to analyse the effectiveness of high intensity group therapy sessions further.

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Breaking the silence: A qualitative exploration of parental perspectives of children with Goldenhar Syndrome

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Introduction: Goldenhar Syndrome (GS) is a rare congenital condition, characterized by craniofacial difference and vertebral malformations. Due to its rare and complex nature, aetiology is unconfirmed, resulting in parental uncertainty and subsequent distress. Clinical manifestations have been researched but few studies have explored parental wellbeing and Quality of Life (QoL). In this qualitative study, we explored parental views and the challenges of raising a child with Goldenhar Syndrome.

Aims & Objectives: We aimed to explore parental perspectives and their lived experiences of raising a child with GS and to understand the QoL challenges faced by their children.

Methods: Ten biological parents (five mothers and five fathers), recruited from Goldenhar UK, took part in semi-structured face-to-face interviews, exploring; responses to initial diagnosis and causation, experiences of stigma and discrimination, the challenges faced, societal awareness, perspectives over time and support received from the Goldenhar UK charity. Reflexive thematic analysis was employed, and transcripts were subject to deductive and inductive coding.

Results /Conclusions: Seven themes were identified: support networks (Goldenhar UK), rollercoaster of emotion; gendered coping; uncertainty; societal reactions; coping with challenges & acceptance.

This is the first-time the perspectives of parents, raising a child with GS have been explored. Prominent issues impacting parental QoL were identified including isolation and distress both at diagnosis, and throughout the multidisciplinary health journey. This research has real-life impact, leading to creation of a Goldenhar family support guide which recently attracted publicity.

Further, we established significant indicators of ongoing QoL challenges faced by young people with GS we explored this further with teenagers, young people and adults with Goldenhar. Development of a QoL conceptual framework is underway and this will be used to develop a bespoke patient reported outcome measure (PROM) to give voice to the challenges children and young adults face during their medical journey.

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Assessment of the need for enhanced recovery pathways for speech surgery

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Introduction/Background: Speech surgery is associated with a significant burden of care and postoperative recovery can be a difficult hurdles for patients and their caregivers. Pain management and resumption of oral feeding can be challenging to navigate in the immediate postoperative period. Enhanced recovery is an emerging area of interest in cleft surgery and has been shown to decrease hospital length of stay, peri-operative opioid use and time to feeding following primary palatoplasty. There is currently limited evidence to support the use of ERPs in speech surgery. The aim of this study was to assess patient, caregiver and healthcare provider experience of secondary speech surgery with a view to co-creating an ERP for these procedures.

Methods: Cleft nurse specialist records were reviewed and a thematic analysis was performed to identify areas of concern for patients and caregivers in the perioperative period. Surveys were created and distributed to caregivers and healthcare providers in cleft centres in Ireland, the UK and North America.

Results: Eleven caregivers and twenty-one healthcare providers responded to the survey. The majority of units surveyed did not have a formal ERP for speech surgery. Pain and resumption of oral feeding were the most difficult aspects of care noted by both caregivers and healthcare providers. Caregivers identified ward visits and additional supports (i.e cleft nurse specialists, play therapy) as important aspects to improve overall in-hospital and recovery experience.

Conclusion: This study emphasises the need for formal ERPs in Speech Surgery. The overlap in both patient and caregiver and healthcare provider concerns highlights key areas to target with these programmes.

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The Development of an Early Language Intervention for Children with Cleft Lip and or Palate

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Background: Recent research reveals a large proportion of children with cleft palate also present with underlying linguistic deficits.

Parents can be coached to increase communicative behaviours which facilitate language development. Parent-child interaction therapy approaches encourage frequent, familiar, repetitive and salient language models for young children. These therapy approaches are commonly used by Community SLT services.

Cleft SLTs are in a unique position to identify language delay in young children, often before Community SLT Services accept referrals. Rather than taking a ‘watch and wait’ approach, the Newcastle Cleft SLT Service wanted to provide early intervention for children identified with language delay.

Aims & Objectives: To develop an effective, time-efficient, Early Language Intervention.

Methods

- At our early years pathway visits (12-24 months) we introduced the standard use of the Communication and Symbolic Behaviour Scales – Developmental Profile (CSBS-DP) checklist to identify children at risk of language delay.
- We offered the parents / carers of identified children remote Early Language Intervention, consisting of 3 to 4 weekly phone calls.
- During each call the following core strategies were introduced:
    - ‘Switch it off’ and ‘Floor time and Play’
    - ‘Observe, Wait, Listen’

  - ‘Keep it short and simple’ and ‘Add words’
  - ‘Questions and routines’
- These were supported with a leaflet and a youtube video (produced by the Newcastle Paediatric SLT Team).
- An additional visit was offered if there were concerns over the child’s main area of need, if calls had been missed, or the SLT wished to demonstrate strategies in person.
- A pre- and post-therapy questionnaire was distributed to monitor the effectiveness of this approach.

Results / Conclusions: A time-efficient Early Language Intervention programme has been designed to support young children’s language development. Data collection will continue in order to evaluate the effectiveness of this approach.

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A simple poster with global impact

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Background: It is estimated that worldwide, a child is born every 3 minutes with a cleft condition.
Delayed diagnosis can be devastating to parents. Associated health issues include poor feeding, failure to thrive and psychosocial dimensions.

Without treatment in some countries, cleft conditions can be fatal. Those who survive, may face years of painful bullying and isolation.

A poster was designed as a quality improvement tool, highlighting the importance of early cleft recognition and identification in the Evelina London Cleft Service (ELCS) areas and reduce the risk of undiagnosed cleft at birth. Its success has had a domino effect, and in collaboration with the charity Operation Smile, is now part of a global education project across Africa and beyond.

Aims: To produce a simple, visual teaching tool to spotlight feeding issues related to a cleft palate, effective palate examination and signpost for further support.

Methods: The poster was distributed around ELCS units within South Thames and prominently displayed for staff to access. Qualitative feedback forms were sent for use and impact of the poster.

Operation Smile used the poster as a foundation for education materials in Africa and beyond, offering an economical and sustainable solution to community training.

Results: The posters were welcomed by ELCS units and the qualitative evidence showed they were utilised to support staff without detailed knowledge of cleft, having a positive impact on approaches to palate examination and the cleft pathway.

Globally, it has been used extensively in train-the-trainer teaching with Operation Smile across Africa, distributed to operatives in outreach communities, providing teaching to families and non-medical staff. The training has initiated an education video filmed in Madagascar, demonstrating palate examination, feeding and support offered by the charity.

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“It hits different” – reflections on study participation where researcher and participant have a cleft

Miss Danielle McWilliams[1]
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Background: Knowledge about the importance of lived experience within research planning, conduct and evaluation is growing. Research designed and led by an individual with lived experience of cleft lip and/or palate (CL/P) is rare, but the impact of peer-to-peer support and contact is well documented in both US and UK-based studies. This study aimed to explore reflections and feedback from study participants with CL/P taking part in a narrative photovoice project, whereby the primary researcher has a CL/P. Implications and potential lessons for research and clinical practice are discussed.

Method: Following participation in a larger narrative photovoice project, 11 women aged 20-72 provided feedback specifically relating to the researcher’s lived experience position via an online survey. Data from the original project containing reflections on the experience of taking part were also extracted. Reflexive thematic analysis was conducted to identify themes in the survey responses and interview excerpts.

Results: Preliminary analyses identified three overarching themes; 1) ‘Unmatched understanding,’ whereby participants spoke of the shorthand within the interaction due to the researcher being able to relate and understand what participants were saying, encouraging them to provide richer, highly personal narratives, 2) Managing emotions, relating to participants’ feelings of safety and comfort with the interviewer and appraisal of how questions were managed both in the interview and in the conduct of the project, and 3) Therapeutic consequence, which included comments about how the experience of participating felt helpful on a personal level, through co-constructing narratives and sense-making with someone with similar experiences.

Conclusions: Individuals with CL/P benefit from peer-networking opportunities. However, results of this analysis provide insights and guidance for future academic and clinical endeavours. There are clear benefits to this approach if thought is afforded to potential challenges such as social desirability, appropriate self-disclosure and the wellbeing of participants and researchers.

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The use of Matriderm dermal substitute as an adjunct in primary cleft palate repair

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Introduction: Primary cleft palate surgery is a time-dependent procedure critical for restoring normal speech and function. A common challenge during surgery is the closure of lateral releasing incisions, made to mobilize the oral flaps. Secondary healing can result in a scarred palatal edge, leading to maxillary arch collapse and long-term growth restriction. This study explores the use of a dermal matrix to optimize the closure of these incisions, aiming to minimize secondary contraction.

Methods: This retrospective study was conducted at Al Jalila Children’s Hospital from January 2022 to December 2024. It involved 20 patients with mean age at surgery 10 months(9-18) who underwent primary cleft palate repair with lateral releasing incisions. Patients with syndromes or other facial anomalies were excluded. After repairing the cleft palate, Matriderm dermal substitute matrix was applied to the lateral incisions, secured with absorbable sutures. Postoperative outcomes, including wound healing, scar and functional recovery were assessed.

Results: A total of 20 patients with primary cleft palate were studied, of which 19/20 patients had adequate oral intake by day 2 post surgery. The lateral gaps showed improved epithelialization and arch closure of >50% at 1 week and >80% at 2 weeks. At the 2-week follow-up, all patients showed improved healing, with no palatal arch collapse or tight scarring.. The matrix facilitated better tissue integration and smooth contour. No infections, secondary bleeding, or scaffold rejection occurred. A 1-year follow-up revealed well-maintained arch and palatal edge contours.

Conclusion: The application of Matriderm in lateral releasing incisions during primary cleft palate repair significantly improves wound healing, maxillary arch retention and mucosalisation. This technique could enhance postoperative recovery and long term arch contour. Larger long term studies are required to monitor for facial growth. Technical details in its application and tips for success will be presented.

Does attendance at early speech-dental groups impact speech articulation and dmft outcomes at 5 years?

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Background: Children with cleft palate ± lip (CP±L) face significant challenges in speech development, with 20% having unintelligible speech by age 5. Early interventions, including parent-driven therapy for children under 3, have proven effective. Dental care is also crucial, as early oral health impacts long-term outcomes. At our cleft centre, we run a parent group focused on speech and dental care guidance post-primary cleft surgery.

Methods: A cohort of 28/43 children born in 2018 was evaluated to compare attendance at the parent group with speech and dental outcomes at age 5. Parental knowledge was assessed pre- and post-intervention through questionnaires. Speech and dental outcomes were measured using CAPSA and dmft scores. Data on speech therapy and hearing were also collected.

Results: Of the 28 children, 25 attended the parent group. Despite this, 15/25 (60%) had a dmft score higher than 1, and 5/25 (1,5%) displayed mild to moderate cleft-related speech characteristics per CAPSA. Additionally, 6.7% of the cohort had speech therapy and hearing difficulties. Parents reported increased knowledge and satisfaction with the support provided.

Conclusions: Attendance at the early intervention group showed no significant impact on improved speech or dental outcomes at age 5. High DMFT scores highlight the need for greater focus on dental care.

Implications: This study underscores the importance of ongoing parental support, particularly in dental care management. It is important to consider the context of the COVID-19 pandemic, which likely disrupted access to local dental care and speech therapy. Future studies should collect additional data, including outcomes for children whose parents did not participate in the early intervention group, to better understand its effectiveness.

References
Lane, H., Harding, S. and Wren, Y., 2022.
Grewcock, R.E., Innes, N.P., Mossey, P.A. and Robertson, M.D., 2022.

Obstructive Apnoea-Hypopnea Index as an indicator for postoperative obstruction in infants with Pierre Robin Sequence

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Background: Pierre Robin Sequence (PRS) is a congenital condition characterised by a triad of micrognathia, glossoptosis and upper airway obstruction, with or without cleft palate. Prior to repair at 12-13 months, all PRS patients have a pre-operative cardio-respiratory sleep study (CRSS) to assess surgical readiness, as per local pathway developed in March 2023. Patients with a “normal” result proceed with surgery and the decision whether a Nasal Pharyngeal Airway (NPA) is inserted is made post-operatively by the anaesthetist. Neonatal categorisation of PRS type (as per Cole, Lynch and Slator, 2008) is used as a predictive factor.

Aims and Objectives: To analyse whether Obstructive Apnoea-Hypopnea Index (OAHI) on CRSS indicates readiness for palate repair and can predict NPA requirement and high-dependency level care postoperatively.

Methods: A retrospective study analysis of all patients with PRS at the Salisbury site of the Spires Cleft network, born between 2019- 2024. This totalled 28 patients for analysis, although 2 patients were excluded due to having a tracheostomy. The pre-operative OAHI value was compared against PRS type and NPA requirement postoperatively.

Conclusion: The study highlighted an inconsistency in referral for a pre-operative sleep study, notably in the earlier cohort. There was a greater consistency of sleep study referrals from 2021 onwards, although due to geographical location and CRSS availability, some patients only underwent pulse oximetry studies that do not measure OAHI. Development of a local pathway improved this, demonstrating the importance for a standardised approach. From the cohort, 6 patients required an NPA postoperatively to date; these patients spanned PRS Types 1-3 with pre-operative OAHI ranging from 0.3-1.6. The study demonstrates poor reliability in using neonatal categorisation as a predictor of post op NPA requirement, yet there is insufficient data currently to prove the significance of OAHI values and a wider study is required.

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Predicting outcomes for features of Velopharyngeal Dysfunction identified at 2-year speech assessment

Ms Elaine O'Connor, Tracey Cooper

Introduction: In Trent Regional Cleft Network, children identified with potential Velopharyngeal Dysfunction (VPD) at their 2-year speech assessment wait for a lateral video-fluoroscopy (LVF) before secondary speech surgery decision making. It usually takes over a year for children to cooperate for this, introducing a significant delay between diagnosis of VPD and surgical treatment.

Aims/Objectives:
- To review the outcomes of children identified as having VPD at their 2-year speech assessment.
- To investigate if there are findings at a 2-year speech assessment that would facilitate earlier speech surgery.

Method: Children born with a cleft involving the palate between 2010-2020 with features of VPD at their 2-year speech assessment were identified. Clinical records were reviewed to extract data on speech assessment, LVF, surgical management and speech outcomes.

Results: 273 children had a 2-year speech assessment between 2010-2020. 37 (13.6%) of these children showed features of VPD. 35 (94.6%) subsequently had a LVF. Secondary speech surgery was recommended for 33 (89.2%) of the children identified with VPD.

19 of the children (51.4%) had more severe features of VPD (nasal realisations, non-oral consonants or absent pressure consonants) and could engage with LVF before age 4. Speech surgery was recommended for all 19 children (11 Furlow palatoplasty, 7 buccal flaps, 1 Hynes pharyngoplasty) of which 17 had a post-operative speech assessment. 13 had a good speech outcome, 1 had some improvement and required further surgery, 3 showed no change and required further surgery.

Conclusion: Speech features of VPD in 2-year-old children post palate repair correlated with a need for secondary speech surgery. If features of severe VPD were found, 100% of children underwent secondary speech surgery.

Compliance with LVF delays surgical treatment after diagnosis of VPD at 2 years old. We will discuss strategies to reduce the age of surgical decision-making in early diagnosed VPD.

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Patient-Reported Outcomes using the CLEFT-Q: Results from a Pilot Study

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Background: Orofacial clefting is one of the most common congenital anomalies worldwide and the most common facial birth anomaly. Individuals with cleft lip (CL) and/or cleft palate (CP) may undergo multiple interventions from birth to adulthood including lip/palate repair, orthodontics, orthognathic surgery, and speech/nasal/audiological surgery. Despite advances in surgical measures and multidisciplinary approaches, studies have highlighted that additional support is often required in this cohort once they reach adulthood.

Aims & Objectives: To explore Patient-Reported Outcomes (PROs) using CLEFT-Q at a cleft clinic.

Methods: Data were collected in Greater Glasgow and Clyde (GGC) (June 2022-June 2023) and analysed in Dundee Dental Hospital (July-September 2023).

Participants were adults who had surgical repair of CL and/or CP completed between 1990-2005.

The project coincided with Cleft Care Scotland 20-year follow-up audit clinics. A validated questionnaire (CLEFT-Q) was used.
Collected data were scored (Rasch analysis) as per CLEFT-Q User Guide.

Descriptive statistics were used to describe characteristics of data recorded. SSPS statistics (www.IBM.com), Kendall's Tau correlation coefficient and Bonferroni corrected Mann-Whitney tests were used to interpret data ($p<0.05$).

Results/Conclusions: 21 participants with cleft lip and palate (CLP) (13), CL (6), CP (2), were recruited (14 female, 7 male) between 17-32 years of age. The small CP group was excluded from further analyses due to size. Male participants reported higher satisfaction rates than females across all scales. No significant differences amongst cleft phenotypes were noted ($p<0.05$). The distribution of converted scores was similar across categories of CLP and CL.

In this patient cohort and limited sample size, excluding CP from analyses, across all domains and scales of CLEFT-Q:

1. There were no significant differences between cleft phenotypes ($p<0.05$)
2. The distribution of converted scores was similar across categories of CLP and CL.
3.

Overall, adult male participants with OFC had more positive PROs than female counterparts.

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Current UK Cleft Centre Practice Regarding Clinical Geneticist Involvement in the MDT

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Background/Introduction: Clinical genetics forms an integral part of the Cleft MDT and is a specified service requirement of every UK Cleft Centre. At age 20, all patients are offered genetics counselling, however, what seems to be less clear is the timing of their referral and review after their first cleft MDT appointment. Due to high demand, patients may wait up to one year to be seen following referral in some services which may increase parent anxiety.

Aims & Objectives: The aim of this study was to survey current practice amongst UK cleft centres with regards to involvement of clinical geneticists in the Cleft MDT and its implications for patient care.

Methods: A national survey was designed and distributed to all UK cleft centres using SurveyMonkey. Responses were collected, analysed and compared to the current practice within our service.

Results: The waiting times to see a clinical geneticist from the point of referral can be up to one year in our service. Our service does not have a clinical geneticist present in cleft MDT clinics and would typically only make an earlier referral in cases suggestive of a syndrome or associated comobordity. Microarray-based comparative genomic hybridisation is routinely requested and completed prior to initial review by our clinical genetics team. Other UK services seem to be delivering much quicker turnaround times with varying referral criteria reported.

Conclusion: Clinical genetics forms part of the overview of management provided to each patient born with a cleft of the lip and/or palate. The difference in current practices amongst UK cleft centres is worthy of further investigation as it has implications for each service, its patients and the equality of care delivered nationally.

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Lateral Segment Mucosal Excess Reduction in Incomplete Unilateral Cleft Lip

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Background/Introduction: Unilateral cleft lip encompasses a wide spectrum of deformity which may present with both deficiency and surplus of tissues. In complete unilateral cleft lip, the lateral or lesser segment is hypoplastic in both bone and soft tissue with reduced volume and deficient mucosal show on the cleft side. Strategies for addressing primary and secondary volume asymmetries have focused on augmenting deficiency as this is more common. Unusually, in incomplete unilateral cleft lip, the lateral segment can be bulkier and a frequent complaint of patients in their later years. In an attempt to address this feature, the senior author has been excising a wedge of horizontal wet mucosal tissue from the lateral lip segment since 2005.

Aims & Objectives: We describe a technique for achieving better volume symmetry at the time of primary lip repair through reduction of excess wet mucosa below the level of the wet-dry junction.

Methods: Markings are performed using the surgeon's preferred repair technique (the senior author's preferred technique is a modified Tennison (straight line) repair with Randall (cutaneous) and Noordhoff (dry mucosal) triangular flaps just above the white roll and wet-dry junction, respectively). After completing the surgical marking of both skin and mucosa, a horizontal wedge is designed from the incision margin on the non-visible wet mucosa usually just posterior-caudal to the wet-dry junction.

Results/Conclusions: We have reviewed the records of 10 cases with mean time of 15 years and 8 months from primary surgery. None have so far requested revision or had adverse scarring. This minor modification can be applied to any surgical markings and has good long-term outcomes with no adverse complications reported.

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Buccinator Flap Pedicle Management: To Divide or Not Divide?

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Background/Introduction: The buccinator flap has become a workhorse procedure for palatal lengthening surgery in the treatment of cleft and non-cleft velopharyngeal dysfunction, however, there is currently no consensus on how the pedicle is best managed post-surgery. This study provides a comparative analysis of two approaches—routine pedicle division versus case-by-case management in which the pedicle is not divided—based on data from two surgeons (AS, PM).

Aims & Objectives:
1. To evaluate and compare clinical outcomes, patient satisfaction, healthcare costs, and operational efficiency of these two different approaches.
2. To examine age-related and patient-preference factors influencing choice of anaesthesia.

Methods: Data from 41 patients was analysed: 17 treated with routine pedicle division (AS) and 24 managed with a case-by-case approach (PM). Post-operative complaints, follow-up requirements, and costs involved were examined. Anaesthesia choices were analysed, with local anesthesia (LA) used in suitable older teenagers and general anesthesia (GA) preferred in younger patients. Qualitative data from patient notes, anaesthesia records, and parent feedback were incorporated to contextualise findings.

Results/Conclusion: Routine pedicle division resulted in minimal post-operative complaints, higher patient satisfaction, and predictable scheduling, albeit with higher upfront costs. Case-by-case management avoided an additional routinely planned procedure in the majority of cases but required more follow-up. Subsequent divisions in the latter group were planned in symptomatic cases or cases in which further surgery was already planned. Patients under the age of 12 all had their pedicles divided under GA to ensure procedural control and reduce anxiety, while some older teenagers underwent division under LA in an attempt to reduce recovery time and the risks associated with GA. These findings provide some insight into these two different approaches to managing the buccinator flap pedicle for cleft patients undergoing speech surgery.

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The value of a Cultural Consultation in enhancing awareness of working with refugee families.

Dr Aimee Pudduck[1], **Miss Jade Evans**[1], Dr Tom Henwood[1], Miss Ari Corbett[2], Dr Nistor Becia[3], Miss Lowri Jones[1]
[1]Welsh Centre for Cleft Lip and Palate, Swansea, [2]Cardiff University, Swansea, [3]Swansea Bay Health Board, Swansea

Background: A Ukrainian refugee family attended for a Cleft MDT consultation. The nature of this initial consultation and some evident psychological distress at this time, made the team aware of the need to seek advice of how to better support this family through a cultural lens. As a result, a cultural consultation was sought.

Aims & Objective: To better understand the cultural needs of the family, to enhance engagement and ensure that the team were using a trauma-informed lens.

Method: A Ukrainian speaking clinical psychologist from the same cultural background who had worked extensively with the Ukrainian refugee population in South Wales was approached and a series of consultations followed.

Result: Following consultation an easy read leaflet was produced for the family. A direct consultation with the Ukrainian speaking psychologist, as well as a more culturally sensitive psychological approach was offered. A culturally informed formulation was shared with the wider Cleft team.

Conclusion: This highlighted the importance of being both culturally sensitive and trauma informed as a team.

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Using a Team Formulation Approach within Cleft Services: A Case Study

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[1]Welsh Centre for Cleft Lip and Palate, Swansea, [2]Cardiff University, Cardiff

Introduction: The Welsh Centre for Cleft Lip and Palate Team were working with a service user with a complex trauma history who presented with difficulties in engaging in aspects of their care. This resulted in debates within the team about how to best support their cleft care needs.

Aims: To bring the team together to discuss the case, taking into consideration all professional viewpoints, whilst being sensitive to the client's background and current experience.

Method: The Lake (2008) Team Formulation Consultation Model was used as the format for this case discussion, using a 4-phase model: Phase 1- History Taking; Phase 2- Cyclical Formulation; Phase 3- Our feelings and Transference; Phase 4- Service user Strengths and Resources.

Results: A formulation was developed following the discussion centred around the 4 phases. Staff were surveyed before and after this intervention, which revealed staff felt more confidence, compassionate and better informed about how to work with someone with a complex trauma history.

Conclusion: This was a novel approach within the cleft service, especially with such a broad professional MDT (including administrative staff). This is usually an intervention caried out with mental health professionals. This was a well-received intervention that helped the team work in a more trauma-informed way. It was agreed that this should be rolled out to use with other complex case presentations.

References: Lake N. (2008). Developing Skills in Consultation 2: A team formulation Approach. Clinical Psychology Forum, 1 (186), 18-24.

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Examining prevalence of bullying using the strengths and difficulties questionnaire.

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Background: Clinical psychologists working in cleft lip and/or palate (CLP) have historically agreed to use the strengths and difficulties questionnaire (SDQ) at routine audit time points of 5, 10 and 15 years old as a screening tool for psychosocial functioning. Bullying is a pervasive issue that impacts the emotional well-being of young people and rates of bullying in cleft vary, according to studies. Nevertheless, anecdotally, parental concern in clinics about this issue remains relatively high. The SDQ has not previously been used to examine bullying prevalence in cleft.

Aims & Objectives:

- To examine the prevalence of bullying in our local CLP population (young people under the care of the Evelina London Cleft Team).
- To investigate any differences in prevalence at age 5,10 and 15, between parent and child reports and examine how the rate compares to that observed in the non-cleft population.

Methods: Using existing accrued data, we performed descriptive statistical analysis to look at rates of self and parent-reported bullying experiences of children with CLP aged 5, 10 and 15, using answers to question 3 from the prosocial scale on the SDQ measure.

Results: Provisional analysis shows parental reports of bullying vary from 2% at 5 years to 8.5% at 10 years and 5% at 15 years. Parental reports are slightly higher than child reports at age 15. Therefore, the rate appears highest at age 10, and lowest at age 5, and aligns with general population rates.

Conclusions: This small-scale study shows how one question on the SDQ can examine rates of bullying. It indicates that bullying is an issue for our patients, but at rates similar to the general population and at rates consistent with clinical experience. These results are helpful to reassure parents and will inform future more detailed analysis of bullying in our patients.

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Bilateral Facial Squamous Cell Carcinoma in an 89-Year-Old Man, Case Report and Review of Reconstruction

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Background: Non-melanoma skin neoplasms generally account for more than 80% of occur in people in their 7th decade of life or higher, and increasing prevalence has made them a global concern. Squamous cell carcinoma (SCC) is the first step of the group of neoplasms mentioned above. An appearance of typical cutaneous squamous cell carcinoma (CSCC) is a non-healing, usually progressively enlarging erythematous papule, plaque, or ulcer. The surgeon should excise such lesions for cosmetic reasons and then schedule second or third operations for flap-mediated reconstructions.

Aims & Objectives: Reporting a novel case of bilateral neglected invasive SCC in an older man, primary repair by cervicofacial flap and reviewing the current surgical approaches for head and neck CSCC.Methods: After reporting a novel case of bilateral neglected facial invasive SCC affecting the parotid region in an 89-year-old man whose treatment with a semi-therapeutic palliative approach, we have conducted a review of facial CSCC from the aspects of epidemiology, staging, and therapeutic management.

Conclusion: The surgeons should weigh against the outcome of their approach. For instance, in the case of older people and the risk of multiple general anesthesia, a palliative approach can be considered.

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Speech post orthognathic surgery in the cleft palate population. Phase one: Report of speech outcomes

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Background: Orthognathic surgery in the cleft palate population can impact velopharyngeal (VP) function (Sales et al, 2021) and improve dentalisation errors (Tsang et al, 2022). In the South West Cleft Service (SWCS), we aim to carry out speech assessments before surgery to facilitate informed consent and after surgery to determine further clinical management.

Aims: To report speech outcomes post orthognathic surgery in the cleft palate population within the SWCS to inform service development.

Methods: 42 patients' pre and post orthognathic surgery speech assessments were analysed and a velopharyngeal competence (VPC, Pereira et al, 2020) score was calculated, whereby VPC0/VPC1 reflect 'sufficient', VPC2 'borderline' and VPC3/VPC4 'insufficient' VP function. Pre and post surgery dentalisation scores were also compared.

Results: Out of 42 patients, two patients' VPC score improved, 29 patients' VPC scores did not change, five patients' VPC scores decreased minorly (three changed from VPC0 to VPC1 (both still within the 'sufficient' category) and two changed to 'borderline' from 'sufficient'). Two patients' VPC score decreased majorly (to 'insufficient', one from 'borderline' and one from 'sufficient'). Four patients had incomplete assessment scores at pre-op, but all four scored VPC1 at post-op.

16 patients showed improvements in dentalisations, 24 remained the same and two patients' dentalisation errors increased.

Confounding factors such as cleft type, procedure type (maxilla only or bi-maxillary advancement) and advancement size were considered. However, no association was apparent upon visual inspection and the sample size was insufficient for statistical analysis.

Conclusions: This project adds to the evidence base that orthognathic surgery can both improve dentalisation errors and decrease VP function, though for most patients, VP function after surgery remains ‘sufficient’ or ‘borderline’ and very few patients request or require further clinical management.

Phase two of this project will be updating the care pathway for this client group.

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Speech outcomes in bilateral cleft lip and palate: a journey through the literature

Ms Stephanie Van Eeden[1], Ms Amy Cable[3], Ms Sharon Baker[2], Ms Hannah Chandler[3], Ms Julie Davies[4], Ms Hannah Lane[5], Ms Claudine Milligan[6], Ms Nicole Prendeville[7], Ms Niamh Ward[8], Ms Caroline Williams[9], Ms Suzanne Wood[6], Dr Lucy Southby[3]
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Background: Bilateral cleft lip and palate (BCLP) is considered the most severe presentation of clefting. BCLP comprises approximately 10% of cleft births each year. Patients with BCLP are thought to have poorer outcomes compared to other phenotypes, but furthering our understanding of this through research is hampered by small numbers.

Aim: To understand the range of reported outcomes for people with BCLP in terms of velopharyngeal function and articulation and to identify gaps in research.

Method: A scoping review was undertaken of papers published between January 2001 and March 2021. Papers were screened by title, abstract and full text. The following inclusion criteria was applied: peer reviewed articles only; those which have clear speech data for non-syndromic BCLP; published in English; all age groups. Data were charted in terms of outcomes for articulation and velopharyngeal incompetence (VPI), with comparisons with other cleft phenotypes where possible.

Results: 72 papers were included in the final analysis. VPI was reported in 6-74% of children of all ages. Reported difficulties with articulation ranged from 50-89% in the preschool years and 33-89% in the primary school age group. Findings compared to other cleft phenotypes were mixed and inconclusive. Significant gaps in the research of speech outcomes in BCLP were noted due to poor methodology, inconsistent reporting of demographics and outcomes, little focused attention on specific difficulties faced by those with BCLP and what interventions may help.

Conclusion: Rates of speech difficulties in BCLP are frequently reported to be high across all ages. However, wide ranges in outcomes reflect poor methodology of many studies. From the current evidence it is not possible to conclude that poorer reported outcomes are due to a diagnosis of BCLP alone compared to other cleft phenotypes. More robust research is needed with larger focused phenotypical groups accounting for all covariables.

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Language Skills of Adults and Adolescents with Cleft lip and/or Palate: A Scoping Review

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Background: There is growing evidence in children with cleft lip and palate (CLP) of increased difficulties with language compared with peers. However, it is less clear whether language difficulties continue into adulthood.

Aim: To explore the quantity, nature and outcomes of research in this area.

Method: A scoping review was carried out using the PCC framework: Population (adults with CL/P), concept (language skills) and context (any country, any year). Papers were screened by title, abstract and full text. Key study features were charted including participant characteristics, country and year of study, methodology and results.

Results: There were 20 papers available for final data analysis. Only three papers were published prior to 2000 demonstrating some increased interest in this topic in recent years. The majority of papers were from North America and the UK. The average age of participants was 23 years (range 16-46 years). Nine papers provided only a qualitative comment on language skills. Five papers reported standardised test results; 4/5 reported lower language levels compared with peers and one reported difference across cleft types. Seven papers compared neural imaging of adults with CL/P compared to controls; 6/7 reported lower activity in the language centres of the brain in the CL/P group.

Discussion: The limited evidence found in this study suggests that language difficulties may be long term within the CL/P population. However, 40% of studies found were single case studies, only reporting qualitative comments as outcome measures. More robust longitudinal research is needed with larger numbers and with participants from backgrounds representative of the population.

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Therapy Outcome Measure-Velopharyngeal Disorder (TOM-VPD): tracking outcomes and the impact of the COVID pandemic

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Background: The Therapy Outcome Measure for velopharyngeal disorder (TOM-VPD) was developed in Newcastle. Standards for 3-year outcomes were reported at the London meeting in 2019. The TOM-VPD aims to collate data on clinical and well-being outcomes in children with speech sound disorder affected by cleft or velopharyngeal incompetence. It uses the World Health Organisation (WHO) International Classification of Function (ICF) as a framework.

Aim: To compare longitudinal data from 3- to 5-years from a UK cleft centre and explore the impact of COVID on speech and ICF outcomes.

Method: TOM-VPD data were gathered at routine 3- and 5-year reviews.
Data were collated and median scores for birth years 2014-2019 were calculated. Results were compared across the birth cohorts and longitudinally.

Results: Data from 178 3-year-olds were available for analysis. Scores have remained consistent from 2014 to 2019 for 3-year-olds, with standards being met each year.

Data from 138 5-year-olds were available. These showed improvement in speech outcomes from 3-years and consistency in meeting the ICF outcomes in all years apart from 2017, where average scores fell 0.5-1.0 score below the standard for all three well-being measures. These children would have been entering their pre-school year during the first lockdown period of the COVID pandemic; they will have experienced successive lockdowns and restrictions for the next two years, including their first year of school entry.

Conclusions: The TOM-VPD reflects not only speech outcomes but also the broader psychosocial impact of speech disorder in children with cleft lip and palate. The Royal College of Speech and Language Therapists are supportive of further roll out of this tool.

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Orofacial features of a patient with ADAMTSL4 gene alteration

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Background: In normal function ADAMTSL4 gene is found on chromosome 1 and provides instructions for making a protein found all over the body1. ADAMTSL4-associated ectopia lentis is a rare autosomal recessive condition that is primarily associated with ocular crystalline lens displacement. However, the prevalence of other manifestations of this condition is poorly understood 2.

Aims and objective: The aim of this case report is to highlight the oro-facial features observed in an adult and encourage awareness of the condition.

Methods: A 21 year old male with ADAMTSL4 gene alteration was referred to the department who presented with a class III incisor relationship on a skeletal III base due to a hypoplastic maxilla and prognathic mandible with pan facial asymmetry. This was complicated by a crossbite from lower right second molar to lower left second molar with no displacement and moderate spacing in both arches. Full clinical records and radiographs were taken.

Conclusions: The patient was seen on the orthognathic clinic and is being planned for a bimaxillary surgery. As very little is known about the extra-ocular features associated with ADAMTSL4, this case report may share additional phenotypes and create awareness of the condition.

Reference

1. https://medlineplus.gov/download/genetics/gene/adamtsl4.pdf Accessed: Jan 12th 2025)
2. Knight LSW et al. The phenotypic spectrum of ADAMTSL4-associated ectopia lentis: Additional cases, complications, and review of literature 2022 Sept

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The impact of school absences on children with cleft conditions: Exploring challenges of regular appointments

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Background: Children born with a cleft typically undergo regular periods of treatment throughout their childhood under the care of the multidisciplinary team which frequently disrupt school attendance. Although efforts are made to reduce these absences and to give patients breaks from treatment, they are often unavoidable. Missed school attendance can lead to children being ostracised and excluded from incentive rewards in addition to other elements of general schooling.

Aims:
1. To improve understanding of the impact missed school attendance has on children with a cleft
2. To see if this impact influences children's perception of their cleft

Methods: Questionnaires are distributed to children aged 8-15 and their families during multidisciplinary cleft clinics. The questionnaires covered several key topics including: the impact of appointments on school attendance, the consequences of school absences, and the extent to which participants feel their school is supportive and considerate of their medical needs.

Results/ Conclusions: Quantitative and qualitative analysis of the data from the patient and parent questionnaires will be presented.

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Buccal Fat Pad Flap Hypertrophy in Palatoplasty: A Rare Complication Leading to Obstructive Sleep Apnoea

Miss Katherine Wensley[1], Mr Sipho Simon Nhongo[1], Mr Mark Devlin[1], Mr David Drake[1], Dr Ross Langley[1], Dr Elise Buchan[1], Dr Patrick Mccrossan[1], Ms. Astrid Koenig[1], Mr Andy Clement[1], Mr Haytham Kubba[1], Mr David Wynne[1], Mr Craig Russell[1]
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Background: The buccal fat pad (BFP) is a well-established adjunct in cleft palate surgery, where it is widely used in lateral releasing incisions. Evidence suggests buccal fat pad flaps (BFPFs) offer benefits including faster healing, reduced scarring, and lower rates of velopharyngeal insufficiency.

Objectives: This case report describes a rare complication of BFPF hypertrophy, following use in lateral releasing incision at primary palatoplasty, resulting in severe obstructive sleep apnoea (OSA). We aim to highlight the utility of multidisciplinary investigation and management of persistent OSA in cleft patients.

Methods: Our patient with complete bilateral cleft lip and palate underwent our standard repair protocol of lip adhesion aged 5 months and definitive lip and palate repair at 12 months with bilateral BFPFs for lateral releasing incisions. Postoperatively, the child developed progressive symptoms of OSA, prompting investigations including sleep studies, microlaryngobronchoscopy (MLB), and MRI. MLB revealed obstructing adenoids and a bulky palate, while MRI identified a hypertrophied lipomatous mass within the soft palate. Repeat adenotonsillectomies were performed but failed to resolve symptoms fully. Surgical excision of the lipomatous mass yielded partial physiological and symptomatic improvement. Further nasoendoscopy identified adenoidal pad occlusion and choanal stenosis. Serial dilation of the choanal stenosis and repeat adenoidectomy ultimately achieved symptomatic relief.

Conclusions: This report highlights a rare complication associated with BFPFs, where post-BFPF lipomatous hypertrophy played a role in pathological presentation. Despite this child having recognised adenoidal hypertrophy, contributing to abnormal sleep symptomatology and physiological sleep parameters, the problem was not singular in nature. The authors hope that this case serves as a useful example for the broader Cleft MDT that persistent symptoms and lack of response to standard treatments may stem from an uncommon aetiology.

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Comparing Speech Outcome Methodology: Further Exploration of a Less Resource Intensive Protocol

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Background: Routinely the Cleft Audit Protocol for Speech Augmented (CAPS-A) is used to establish comparisons of speech outcomes. This protocol is well established throughout the UK and is held as the gold standard when evaluating and reporting speech outcomes. Consideration is also given to inter and intra rater reliability and the importance of consensus judgement when undertaking the CAPS-A protocol. In contrast, the GOS.SP.ASS'98 tool is used for the live, independent assessment of cleft speech in a clinical setting. This approach builds on the work of Ahl et al (2018) when considering clinical resources and outcomes.

Aims: The aim of this study is to compare CAPS-A speech outcomes with clinical GOS.SP.ASS' 98 assessments undertaken at the time of pre and post operative assessment and to demonstrate the differences in reliability and validity between the live clinical records and the CAPS-A judgements.

Methods: Analysis of 64 pre/ post operative assessments of patients who underwent orticochea pharyngoplasty surgery under a single surgeon across two cleft centres were consensus listened by two trained Specialist Speech and Language Therapists. These findings were then reviewed against the live clinical GOS.SP.ASS'98 assessments for reliability.

Results / Conclusions: With increasing demands on Speech and Language Therapy services nationally and the time required for highly specialist Speech and Language Therapists to undertake consensus listening the results will be discussed as to their clinical applicability and whether live clinical assessments GOSPASS'98 provide sufficient reliability and validity for reporting speech outcomes.

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Establishing a CNS innovation group to provide evidence based interventions and improve patient care.

Ms Bev Willshire[1]
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Background: Nursing practice needs to be evidence based and ideally standardised (NMC 2023). This is to ensure up to date, optimal care, whilst avoiding conflicting advice for patients and providing a better experience (Davies and Day, 2010). From the twice yearly CEN meeting, a sub group was suggested and formed from volunteers from each team in 2023. We planned to research and review best practice, with the view to refreshing and updating our care. Thus giving our patients the best possible outcomes and experiences. We agreed to chose topics that we were enthusiastic about, had an interest in and needed updating.

Aims & Objectives: The structure and role of the Cleft CNS has evolved over time and we wanted to reflect this, whilst improving patient care. By reviewing our current practices through sharing our experiences, practices and collating robust research to support it, which for cleft specific research was and is evidently limited, we wanted to give the nurses a voice in the care provided to our patients and families.

Methods: Regular group meetings and discussions. Literature searches. Audits. Use of cleft collective for data.

Results /Conclusions: The innovation group provides a space to share ideas across the CNS network, for projects and generate discussions including asking how other teams facilitate and implement the cleft national specifications (NHS, 2010).

So far a poster for highlighting and teaching on delayed diagnosis of cleft palates has been produced and published and backed by CLAPA. Our current project is reviewing and rewriting a feeding assessment for babies with a cleft taking into consideration gestation, positioning, type of bottle and if checking for a gag is necessary and if so why. An incidental anecdotal outcome has been in strengthening the working relationships within the CNS network.

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Implementing a change in Clinical Nurse Specialist's practice for glue removal following cleft lip surgery.

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[1]Guys and St Thomas NHS Foundation Trust, London, UK

Background: An experience of observing non-standardised practise of glue removal post cleft lip surgery from an older child with additional needs, was distressing for the child, the mother and the clinical nurse specialist's (CNS's) involved. The observed practice was long and arduous, using a cotton bud soaked in saline to curl the edges of the glue to remove it manually. An alternative practise observed, was pulling the glue off like a plaster, with a saline soaked piece of gauze. This too usually ended in the patients, and at times parental, upset, but was a quicker process. Both practices resulted in negative oral experiences for the patient and prompted a review of current practice.

Aims & Objectives: To improve the patient and family's experience (Davis and Day, 2010) of post op glue removal.

Methods: The ELCS CNS team practices were shared through discussion. A questionnaire was sent across the UK cleft CNS network to capture other practices. A literature search was conducted, and widened to include general lip and facial wound care, due to limited cleft specific research. Tissue viability considered. Wound care advice from other specialities and information from the glue manufacturer gathered.

Results /Conclusions: A consistent approach was adopted; no longer pulling the glue off, but with washing, and the application of yellow paraffin, the glue would soften and come away spontaneously. This standardised our CNS team's care (NMC, 2023).

We saw this immediately positively improved the experience for the child and therefore the parent. The difficulty came in evaluating the change. A qualitative parental feedback questionnaire was devised asking parents what their preference would be; pulling the glue off or allowing the glue to come away by itself over several days. The results were unanimous, 100% of parents chose to allow the glue to come away by itself.

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Assessing the outcomes and predictors for success of secondary alveolar bone grafts

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Background: Secondary alveolar bone grafting (SABG) is a vital procedure in the management of cleft lip and palate. Cleft care in the UK was centralised following the 1998 Clinical Standards Advisory Group assessment. This study evaluates the outcomes of SABG procedures performed at a regional UK cleft centre.

Aims & Objectives: The main aim of the study was to assess the outcomes of SABG carried out at the Evelina London Cleft Service (ELCS) and investigate whether any factors such as the cleft type, cleft laterality, and whether tooth removal during grafting had any influence on the success of the bone grafts. Additionally, it seeks to identify predictors of successful alveolar bone graft outcomes.

Methods: Any patient diagnosed with a cleft lip and/or palate who had a SABG under the age of 16 years were included in the study. Patients with craniofacial syndromes or those who underwent a repeat secondary alveolar bone graft were excluded from data collection. Data were collected retrospectively over a three-year period (January 2021 – June 2023).

Statistical analysis was performed using SPSS software. Chi-square tests were used to assess any associations, and binary logistic regression to identify predictors of success.

Results /Conclusions: In total, 90 patients and 105 SABG (mean age 10.12 SD 1.45 years) were included in the study. The overall success rate of the SABG included was 85.7%. There were no significant differences in success rates based on the cleft type, cleft laterality, or tooth extraction ($p > 0.05$). None of the variables were significant predictors of graft success.

This finding demonstrated that SABG success rate of 85.7%, was in line with the UK national outcome data. Factors such as cleft type, cleft laterality, and tooth extraction during surgery did not significantly influence alveolar bone graft success.

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