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Abstract Book

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The timing of cleft-adjacent dental extraction for secondary alveolar bone grafting: Scoping review and recommendations

Miss Julie Potter[1], Dr Bethan Edwards[1], Helen Extence[1], Dr Charlotte Eckhardt[1], Dr Mechelle Collard[1], **Mr Matthew Fell**[1]
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Background: Considerations for timing cleft adjacent dental extractions, either before or during alveolar bone grafting (ABG) are important due to their clinical, safety and resource implications. A separate procedure in advance of ABG may reduce the bacterial load, enhancing the amount of keratinised tissue for wound healing, whereas a single combined procedure reduces the morbidity of additional dental and anaesthetic procedures for the child. Comparatively little attention has been paid to this variable and its impact on ABG outcomes in comparison to other well established risk factors.

Aims: A scoping review of the literature to map evidence for the timing of cleft-adjacent dental extraction with ABG and associated outcomes.

Methods: A systematic search of Medline and Cochrane databases from inception to January 2026. The population of interest was humans born with an alveolar cleft, undergoing secondary ABG during mixed dentition. The intervention was timing of cleft adjacent dental extraction; either before or during ABG. The outcome was the presence of postoperative complication or determination of failure following the ABG procedure.

Results/Conclusions: Two studies met the inclusion criteria and were included in the primary analysis. Both studies reported an advantage of cleft adjacent dental extraction in advance of ABG in terms of prevalence of complications and graft failure. A further six studies were included in a secondary analysis, whereby the presence of intra-operative cleft adjacent dental extractions were compared to an absence of dental extraction, with inconsistent results reported on the impact of dental extraction on bone graft failure.
There is limited evidence to conclude whether the timing of cleft adjacent dental extractions substantially affects the outcome of secondary alveolar bone graft. The implication of potential selection bias in the studies analysed also plays a key role. Clinical decisions regarding timing dental extractions should consider dental, patient, safety and resource factors.

Maternal genome-wide association study identifies novel loci associated with offspring orofacial clefts

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Background: Genome-wide association studies (GWAS) have identified over 40 genetic loci associated with orofacial clefts in affected children. However, cleft aetiology may also involve maternal genetic factors acting through the intrauterine environment, independent of variants inherited by the child. Understanding maternal genetic contributions could reveal new biological pathways and potentially modifiable mechanisms underlying cleft development. To date, no large-scale maternal GWAS of orofacial clefts has been conducted.

Aims & Objectives: We aimed to investigate whether maternal genetic variants contribute to offspring orofacial cleft risk independent of effects directly inherited to offspring and to compare maternal versus paternal genetic contributions.

Methods: We analysed genetic data from mothers of children with orofacial clefts (N = 10,203) from the Cleft Collective (UK), meta-analysed with additional maternal data from the University of Bonn (Germany). Maternal GWAS were performed unadjusted and adjusted for offspring genotype to isolate maternal-specific effects. Enrichment analyses characterised biological pathways of implicated loci. A parallel paternal GWAS assessed parent-of-origin specificity.

Results/Conclusions: We identified multiple genome-wide significant loci in the maternal GWAS. The strongest association was at 8q24.21, a region with established cleft associations, which remained significant after adjusting for offspring genotype. Novel maternal-specific loci included variants near CYP51A1P1 (3p12.2), MFAP2 (1p36.13), and CEP43 (6q27). Gene-set analyses revealed enrichment for anthropometric traits, bone tissue density, and cortical thickness. Notably, the paternal GWAS yielded no genome-wide significant associations, suggesting maternal-specific genetic effects. These findings provide the first evidence that maternal genetic variants, acting through the intrauterine environment, independently contribute to offspring cleft risk.

Counselling for families affected by Cleft Lip and Palate

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Background / Introduction: Adults born with a cleft can experience appearance-related concerns, anxiety, depression, and challenges associated with surgery. Parents of children born with a cleft frequently face stress around diagnosis and worry about their child's future. Both groups may encounter ongoing social and emotional challenges that can affect overall wellbeing. In response, the Cleft Lip and Palate Association (CLAPA) established a national Counselling Service to provide timely, accessible, and cleft-informed psychological support. This abstract explores the service's development and its impact on adults born with a cleft and parents of children born with a cleft.

Aims & Objectives: This abstract describes the development of CLAPA's Counselling Service and evaluates its impact on families affected by cleft. Objectives were to outline service growth, analyse engagement patterns, and explore client-reported outcomes and experiences.

Methods: The service launched in 2022 as a co-produced pilot with two student counsellors and expanded to four practitioners by 2025. Families self-referred or were referred by professionals. Service records, including referral data and engagement rates, alongside anonymised client feedback, were thematically reviewed to identify key outcomes and user experiences.

Results / Conclusions: Between 2022 and 2025, 66 families were supported. Clients reported significant emotional relief in "finally being heard" and valued discussing appearance, identity, and broader life challenges. Cleft-informed counsellors, many with lived experience, fostered empathy and trust, enhancing engagement. Benefits extended beyond appearance-related concerns, supporting resilience, mental wellbeing, and family functioning. Findings highlight the importance of specialist, empathetic counselling and demonstrate that community-led services can provide timely, trusted, and cleft-informed support to families.

The impact of variation in age at primary palate repair on structural speech outcomes

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Background: The impact of timing of primary palate repair on structural speech outcomes has been the focus of much research in the field of cleft palate. The recent Timing of Palate Surgery trial compared outcomes when surgery was performed at 6months with those from surgery which was carried out at 12months, however service and/or patient constraints mean that there is often greater variation in the timing of primary palatoplasty.

Aims and objectives: The aim of this study was to examine if and how differences in timing of primary palatoplasty performed before age 15months are associated with development of passive cleft speech characteristics (CSCs) in the speech of children born with cleft palate, with or without cleft lip.

Method: Data from the Cleft Collective were used, specifically surgical forms completed following initial palate repair and speech and language therapy assessment data at age 36months. Logistic regression was performed to assess the association between the presence of passive CSCs and age of child at their primary surgery, with adjustment for child's age at assessment, cleft subtype, biological sex, presence of a syndrome, presence of Robin Sequence, and presence of hearing loss.

Results and conclusion: Data were available for 174 children. The mean age at primary palatoplasty was 9.65 months (standard deviation 2.18). Passive CSCs occurred in 16.7% (n=29) of the sample. We found weak statistical evidence to suggest the odds of having a passive CSC at 36 months increased by 24% for each additional month increase in age at palate repair (OR 1.24; 95% CI 1.00–1.54; p = 0.047), suggesting that in the first 15months of life, small delays in surgery may impact on velopharyngeal function and early speech.

Early Anatomic Factors and the Likelihood for Cleft Speech Characteristics

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Introduction: Cleft speech characteristics (CSCs) are common in children born with a cleft palate with or without lip involvement (CP+/−L) likely due to anatomic variations affecting the craniofacial complex.

Aim: This study aimed to explore how early anatomic factors present within the first year of life influence the likelihood and type of CSCs observed at age 3 years.

Methods: Data comprised 293 children born with CP+/-L who had consented to the Cleft Collective Cohort Study. Anatomic predictors included cleft type (cleft palate only [CPO], unilateral cleft lip and palate [UCLP], bilateral cleft lip and palate [BCLP]), pre-operative palatal cleft width (mm), and post-operative fistula status. Outcomes included the presence of any CSC and CSC subtypes (anterior, posterior, non-oral, and passive). Logistic regression models were adjusted for age at assessment, biological sex, and hearing status.

Results: At 36 months, 64.9% of children exhibited at least one CSC. When compared with CPO, children with UCLP had increased odds of any CSC (OR = 2.12, 95% CI = 1.16–3.90), while children with BCLP demonstrated higher odds (OR = 4.99, 95% CI = 1.89–13.18). Posterior CSCs were strongly associated with cleft type, with increased odds for UCLP (OR = 3.70, 95% CI = 1.72–7.96) and BCLP (OR = 7.27, 95% CI = 2.95–17.90). Each 1-mm increase in pre-operative cleft width increased the odds of passive CSCs by 23% (OR = 1.23, 95% CI = 1.06–1.42). Fistula presence increased the odds of CSCs, including any CSC (OR = 3.12, 95% CI = 1.26–7.73) and passive CSCs (OR = 3.04, 95% CI = 1.37–6.75).

Conclusion: CSCs at age 3 years are influenced by early anatomic factors, highlighting the importance of anatomy-informed risk assessment. Findings could inform individualised surgical and speech intervention strategies helping to optimise speech outcomes in children with CP+/−L.

Development of an adult multi-professional restorative dentistry cleft service

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Background: Adults referred to a Restorative Dentistry service often have multiple dental needs, some of which could be managed in primary care, others requiring specialist input. Increasingly, cleft patients are finding it difficult to access primary dental care, and specialists in restorative dentistry cannot commence with complex treatment until the patient is dentally fit.

Aims & objectives: This presentation outlines the steps required to set up a multi-professional clinic utilising the skill mix of different dental professionals.

Methods: Project management tools are presented showing how the SWOT analysis led to a new proposed clinic within an NHS Trust. Financial projections and risk analyses are shown, along with KPIs and how they were monitored.

Results/Conclusions: The resulting clinic (termed "the supercleft clinic") was set up with a dental clinical nurse specialist (CNS), dental therapist (DT), clinical dental technician (CDT), dental trainees and a consultant in restorative dentistry (CRD). They were collectively able to manage a spectrum of dental needs, overseen but not necessarily treated by the CRD. The benefits of this clinic are highlighted, notably - improved patient access to treatment, reduced waiting times, addressing environmental sustainability and teaching /training opportunities. Challenges in running this clinic and impact on staff and patient experience are also discussed.

Cleft laterality and educational outcomes at age 7 in England: Results from linked national datasets

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Introduction: Additional congenital malformations are more prevalent with right and bilateral cleft lip and palate (CL+P) than left CL+P. Educational outcomes vary according to cleft type, but it is unknown whether they also vary with laterality.
Aim: To compare educational outcomes at 7 years between those with left, right and bilateral cleft lip+/-cleft palate (CL+/-P).

Methods: Children born in England from 2000 to 2007 with a non-submucous cleft were identified in the Cleft Registry and Audit NEtwork Database and linked to the National Pupil Database with consent. Teacher-assessed attainment levels across all five major subject areas were used to determine whether children achieved the expected educational standard at age 7 years. Odds ratios (OR) for receiving special educational needs (SEN) support and achieving the expected educational standard were estimated for right and bilateral CL+/-P compared to left CL+/-P, adjusting for sex and syndrome status.

Results: A total of 2,565 children with CL+/-P and educational data were included. 1,037 had CL only (CLO) and 1,528 had CL+P. Compared to their left-sided counterparts, the adjusted OR (aOR) for receiving SEN support was 1.32 (95% confidence interval (CI) 0.98-1.79, p=0.0652) for right CLO (RCLO), 1.15 (95% CI 0.72-1.84, p=0.5685) for bilateral CLO (BCLO), 1.24 (95% CI 0.97-1.60, p=0.0902) for right CL+P (RCLP) and 1.77 (95% CI (1.38-2.27, p<0.001) for bilateral CL+P (BCLP).
Compared to left-sided clefts, the aOR for achieving the expected standard was 0.83 (95% CI 0.61-1.13, P=0.2333) for RCLO, 0.80 (95% CI 0.50-1.27, P=0.3452) for BCLO, 0.76 (95% CI 0.59-0.99, p=0.0393) for RCLP and 0.69 (95% CI 0.54-0.89, p=0.0039) for BCLP.

Conclusion: Compared to LCLP, children with RCLP and BCLP were less likely to achieve the expected academic standard at 7 years. Laterality appears not to affect educational outcomes with CLO.

Are Current UK Cleft Speech Outcomes Experiencing A Temporary Post Covid Hangover?

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Since the introduction of Cleft Audit Protocol for Speech –Augmented (CAPS-A), UK speech reporting has continuously developed to include reporting of risk adjusted 3-year-cohort national speech standard data by treating centre in funnel plots. This approach allows appropriate inter-centre comparison with the intention of learning from best practice. Data demonstrates significant inter-centre variation but has failed to adequately report longitudinal variation in overall UK outcomes.

This study sought to correct this omission / investigate changes in annual UK speech standard outcomes

Using standard CRANE processes for inclusion and exclusion (1), UK speech-outcome data was collated by individual birth-year cohorts from 2006-2018. Data was analysed for completeness and proportions meeting UK national speech standard (SS1, 2a, 2b, 2c, 2d & 3)

Steady improvement in data completeness was demonstrated from commencement (2006:24%) up to the pre-COVID cohort (2013:71%). The 2014 (52%) and 2015 (28%) COVID-affected cohorts experienced rapid deterioration followed by correction with the 2018 cohort demonstrating the most complete dataset yet recorded (75%). In contrast, outcomes (except for SS2d and 3) peaked with the 2015 birth cohort (2015 – SS1-65%, SS2a-75%, SS2b-83%, SS2c-17%, SSd-13% and SS3-70%). SS2d peaked in 201(11%) and SS3 in 2014 (72%). Despite recovery in data completeness since COVID, data indicate significant deteriorations in the proportion of patients meeting each speech standard apart from SS2a. (2018 – SS1-51%, SS2a-74%, SS2b-52%, SS2c-48%, SSd-14% and SS3-60%)

UK cleft speech data completeness has recovered to and beyond pre COVID levels. Unfortunately, except for SS2a, national outcomes continue to decline from their 2015 peak. This continued progressive deterioration suggests the potential for more

than a temporary COVID related disruption and highlights the need for renewed investigation and targeted quality improvement efforts to restore previous progress in cleft speech outcomes achieved in the UK.

References
1. 2025 Crane Database Annual Report

Understanding transferred cleft care: Frequency, data completeness, and clinical outcomes

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Background: Despite the perceived importance of continuity in cleft care, no published studies have compared outcomes between children who remain in continuous care and those who transfer between cleft centres.
Objectives: To quantify the proportion of children born with a cleft who transfer between cleft centres and to determine whether data completeness and/or outcomes assessed at 5 years differ from those who remain in continuous cleft care.

Methods: Children born 2015-2019 were categorised as receiving continuous care or having transferred care, according to transfer records on the CRANE Database. Measures included data completeness and clinical outcomes for growth, dental health, facial growth, speech, and TIM assessments at 5 years. Proportions were compared using chi square tests.

Results: Of 4,665 CRANE-consented children included, 114 (2.5%) transferred care before 5 years. The proportion of transferred cases varied between services (p=0.036). Data completeness was similar between groups for growth, dental and facial growth assessments. However, children who transferred had significantly lower completion of speech data (53% continuous vs. 28% transferred, p<0.001) and TIM scores (59% vs. 46%, p=0.005). Across clinical outcomes, no statistically significant differences were observed. The proportions of children with healthy BMI, caries experience, extensive caries, normal speech, and speech free from cleft-related articulation difficulties were almost identical between groups. Outcomes for good facial growth and speech without structurally related differences showed larger between-group differences, but these were not statistically significant due to very small transferred care samples.

Conclusions: Less than 3% of children transferred between cleft services before 5 years. Transferred care was associated with reduced data completeness for speech (as expected due to speech reporting protocols) and TIM assessments but did not affect measured clinical outcomes. These findings suggest that while continuity of care may support more complete data collection, transferred care does not appear to compromise clinical outcomes.

Early hearing status is a determinant of cleft speech outcome at age 5.

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Introduction: Early detection of hearing loss and subsequent timely intervention is thought to improve acquisition of speech and language skills in children born with cleft palate +/-lip (CP+/-L). In England, children with CP+/-L are targeted for enhanced hearing surveillance. It is not known if this programme helps ensure normal development of speech by age 5.

Aim: To determine if early hearing status influences speech outcomes in children with CP+/-L.

Method: CRANE-consented children, born in England (2006-2018), with CP+/-L, were linked to their Newborn Hearing Screening Programme records. Screening results were defined as clear response or no clear response. Hearing loss at subsequent audiology assessment was categorised as either conductive temporary or permanent. Speech at age 5 was assessed using cleft speech standards (SS1, SS2a and SS3). Analysis was performed using Chi-squared test and logistic regression, adjusted for sex, cleft type and extent of palate involvement.

Results: Linked data were available for 3,833 children with CP+/-L. Children with conductive temporary hearing loss were less likely to meet SS1 (aOR 0.782, CI 0.670-0.914, p=0.002) and SS3 (aOR 0.794, CI 0.675-0.935, p=0.006) than those without. Children with permanent hearing loss were less likely to meet all three speech standards (SS1 aOR 0.322, CI 0.167-0.621, p=0.001; SS2a 0.383, CI 0.212-0.694, p=0.002; SS3 aOR 0.320, CI 0.168-0.609, p=0.001).

Conclusion: Children diagnosed with conductive temporary or permanent hearing loss at the first audiology assessment after birth were less likely to meet UK cleft speech standards at age 5. These findings suggest that current enhanced hearing surveillance may not be sufficient to mitigate the impact of early hearing impairment on speech development, highlighting the need for timely identification, close monitoring, and targeted intervention to optimise speech outcomes in this population.

The Cleft Dental Care Crisis

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Introduction: Our community consistently tell CLAPA that accessing dental care is one of the most challenging parts of their lifelong treatment journey. Difficulties finding general practice dentists is a major concern for our community. In response, CLAPA launched the End the Cleft Dental Care Crisis campaign to gather evidence, highlight lived experience, and work with clinicians and policymakers on solutions.

Aims & Objectives: To share what patients have reported about their experiences trying to access dental care; to highlight the barriers identified through CLAPA's national engagement and survey work; and to outline the changes the cleft community believe are needed to ensure lifelong access to appropriate dental care.

Methods: CLAPA combined findings from its national dental access survey with testimonies and feedback from our community across the UK, alongside discussions with cleft teams, dental professionals, voluntary organisations and system leaders. These insights were brought together in CLAPA's policy document, End the Cleft Dental Care Crisis.

Results / Conclusions: What our national survey found was that: -
People with cleft are twice as likely to face barriers accessing dental care.
42% report receiving inadequate care due to a lack of training or understanding of cleft.
38% cannot afford treatment for cleft-related dental issues.
7% have been refused treatment outright because of their cleft.

These experiences have real consequences for health, confidence, and wellbeing, and they point to systemic issues rather than individual cases.

CLAPA is calling for four key changes:
Access – guaranteed lifelong NHS dental care for people with cleft.
Training – standardised cleft training for all dentists.
Care – better integration between dentistry and cleft treatment pathways.
Transparency – clear reporting on dental access and outcomes for people with cleft.

These changes reflect what our community believe is necessary to ensure safe, consistent, and fair dental care throughout life.

Dental health outcomes in children with Pierre Robin Sequence

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Background: Children with cleft lip and palate are known to have an increased risk of dental caries when compared to their non-cleft peers. Infants with Pierre Robin Sequence (PRS) face additional anatomical challenges, including micrognathia and glossoptosis, which can complicate early feeding. Anecdotally, paediatric dentists have reported that children with PRS appear to have higher levels of dental caries than children with cleft palate only (CP). It has been postulated that this may be due to infant feeding difficulties those with PRS experience. To date, there have been no studies which have specifically investigated dental caries experience in PRS.

Aims and Objectives: This study aimed to examine differences parent-reported dental health outcomes between children with CP and PRS, specifically assessing differences in infant feeding difficulties, oral hygiene and dietary habits and dental health outcomes.

Methods: A retrospective cohort study was conducted using parent-reported data from the Cleft Collective Research Programme. Questionnaire data from 580 children (402 CP; 178 PRS) were analysed at 18 months, 3, 5, and 8 years of age. Items relating to feeding, oral hygiene, dental attendance, and dental health outcomes were included. Descriptive and inferential analyses, including chi-square and t-tests, were performed.

Results and Conclusions: Feeding difficulties at 18 months were significantly more prevalent in children with PRS ($p<0.001$). No differences were observed in oral hygiene or dietary habits between the groups. However, parent-reported dental outcomes showed higher rates of dental caries ($p=0.05$) and enamel hypomineralisation ($p<0.001$) at 3 years in the PRS cohort. Children with PRS were also more likely to have had dental treatment at 5 years ($p=0.006$) and specialist dental care at 8 years ($p=0.008$).

Children with PRS have poorer dental health outcomes than those with CP and may benefit from targeted preventive dental care. Further research incorporating objective clinical data is required.

Oral Health Outcomes and Shared Care in Children with Cleft Lip and Palate

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Background: Children with cleft lip and/or palate (CLP) are at increased risk of dental caries. In the UK (UK), oral healthcare is expected to be delivered through a shared care model involving general dental practitioners (GDPs) and specialist paediatric dentists (SPDs); however, this pathway has not been formally defined.

Aims: This mixed methodology study aimed to report caries prevalence in children with CLP at 18 months, 3 years and 5 years; investigate associations between clinical, structural and behavioural factors and caries; assess agreement between parental reports of child oral health; and explore facilitators and challenges to shared oral healthcare from the perspectives of patient–parent dyads and dental professionals.

Methods: Quantitative data were extracted from the Cleft Collective cohort and analysed in RStudio. Binomial logistic regression examined predictors of caries at age 5 (or proxy of previous dental treatment), and inter-rater agreement between mothers and partners was assessed using kappa statistics. Qualitative semi-structured online interviews were conducted with 30 participants: 7 SPDs, 10 GDPs and 13 patient–parent dyads. Data were analysed using constant comparison techniques informed by grounded theory.

Conclusions: Of 1,778 children, 1,135 had caries data recorded, with prevalence increasing from 1.55% at 18 months to 17.20% at 5 years. Hypomineralised teeth and fluoride varnish use were associated with caries at age 5. Agreement between parents was high for caries status and brushing frequency, but poor for age of first dental visit. Qualitative findings identified communication, training and locality of care as facilitators of shared care, while lack of confidence and unclear professional roles were barriers. Lower reported caries prevalence compared with previous studies may reflect limitations of parent-reported outcomes and variability in preventive care delivery. These findings support the need for clinical validation and co-design of a clearly defined shared care pathway for children with CLP.

Exploring children's and young people's experiences of cleft lip and palate multi-disciplinary clinics: 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 emphasise including children in healthcare decision-making. However, limited research has explored the perspectives of children and young people (YP) with cleft palate and/or lip (CP/L) regarding the care they receive.

Aims/Objectives: This study explored the views of children/YP with CP/L about their experiences of multidisciplinary (MDT) cleft clinics and their ideas for improving these services. And professionals' opinions on the acceptability and practicalities of implementing changes suggested by children/YP.

Methods: Study 1a used two face-to-face focus groups with nine children/YP aged 8–14 recruited from a national cleft group to investigate their experiences and suggestions for adapting MDT clinics. Data was analysed using Thematic Analysis (TA).

Study 1b involved an online focus group with three children/YP aged 8–14 to gather further ideas for MDT clinic improvement, informed by findings from Study 1a. TA was again used.

Study 2 consisted of a Quality Improvement workshop with four MDT professionals to explore the children/YP's experiences.

Results/Conclusions: Children/YP expressed a desire for greater involvement in their cleft-related healthcare. Three overarching themes emerged: (1) how attending the MDT clinic feels, (2) navigating the clinic process, and (3) weighing the costs and benefits of attending. Children/YP wanted more autonomy, empowerment, and person-centred care within a system that listens to them. Suggested improvements included clearer, child-friendly information, more inclusive communication during consultations, and involvement in decision-making.

MDT professionals were open to implementing changes relating to communication, information provision, clinic environment, and supporting autonomy. Potential barriers included operational constraints, limited space, and differing levels of readiness for change among professionals. Despite a small, convenience-based sample, the study provides new evidence to inform service improvements in Scottish cleft care that are shaped directly by the voices of children/YP.

Secondary Speech Surgery and Outcomes Following Post-Operative Fistulae in Cleft Palate Repair

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Aims: This study evaluated the impact of post-operative fistulae on speech outcomes and the need for secondary speech surgery in children affected by cleft palate ± lip (born 2013-2017, treated by two surgeons).

Methods: A retrospective review of prospectively collected palatal fistula and CAPS-A speech data was conducted. Children with named syndromes (n=14) or lost to follow-up were excluded (n=4). Speech outcomes were assessed between 5.0-5.11 years (mean 5.5 years), using the standardised CAPS-A protocol (Sell et al. 2009). Outcomes including hypernasality, nasal emission, turbulence, passive cleft speech characteristics (CSC), and secondary speech/fistula surgery rates were recorded and analysed.

Results: 179 children were eligible for inclusion. Post-operative fistula rate was 7% (n=13). 88 children (49%) fully completed the CAPS-A speech assessment. No difference existed in percentage completing ($p=0.16$) or age of CAPS-A assessment ($p=1.0$). Children with a fistula had wider pre-operative hard-soft junction measurements (13mm vs. 10mm; $p<0.05$). There was no difference in the proportion of children with evidence of hypernasality, nasal emission, turbulence, or passive CSCs at age 5 (8% vs. 5%, $p=0.4$). Overall rate of secondary speech surgery was 22%. Those with a fistula were more likely to require secondary palatal surgery (78% vs. 19%; $p<0.05$). Among those who had revision surgery, a greater proportion in the fistula group achieved normal speech post-surgery (88% vs. 46%, $p=0.08$).

Conclusions: Pre-operative anatomy and post-operative fistulae following cleft palate repair are associated with increased likelihood of secondary surgical intervention. Within the cohort of patients with fistulae, appropriate identification of need, timing, and execution of secondary surgical and speech therapy intervention can lead to comparable speech outcomes at age 5. However, the cohort of children requiring secondary surgery in the absence of a fistula may represent a more complex group, with tendencies towards poorer speech outcomes, despite intervention with secondary speech surgery.

A comparative study of scar outcome of two suture techniques for cleft lip repair

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Introduction: Transcutaneous suturing to the skin is typically used in cleft lip repair. However, this can cause potential cross-hatching on the skin with a poorer aesthetic appearance. Using a transdermal suture technique for skin closure and dermabond as the final layer of closure instead of skin sutures can help prevent cross-hatching on the skin and achieve an excellent scar with good aesthetic appearance.

Aim: This study aims to compare the scar outcomes between transdermal and transcutaneous suture techniques in unilateral cleft lip repair.

Method: Fifty patients were randomly selected, and their five-year post-operative frontal photographs were reviewed by a panel of 56 blinded surgeons and lay reviewers using a five-point Likert scale.

Results: Both surgeons and lay reviewers assessed better outcomes for transdermal suture compared with transcutaneous suture. The mean Likert score for surgical / lay assessors was 2.20 / 2.28 and 2.85 / 2.76 for transdermal and transcutaneous suture respectively. This difference was statistically significant ($p<0.05$). However, between the two groups there is no statistical significance between scores given by surgeons and lay reviewers for either suture technique. The inter-rate reliability in both groups are excellent with intra-class correlations of 0.904 (95% C.I. 0.863 – 0.937) and 0.922 (95% C.I. 0.889 – 0.948) for surgeon and lay reviewers respectively.

Conclusions: Preliminary results have demonstrated that transdermal suture technique has shown good scar outcome with excellent aesthetic appearance. This technique can be considered as an alternative to the traditional transcutaneous suture with minimal scarring.

Psychological and Quality-of Life Outcomes Following Orthognathic Treatment in a UK Cleft Service

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Background: Orthognathic treatment is associated with improvements in perceived facial appearance and psychological wellbeing (Wang et al., 2024). Previous studies have reported increased social confidence following surgery (Cadogan & Bennun, 2011). Improvements in psychological wellbeing have also been linked to better oral health–related quality of life after orthognathic treatment (Feitosa et al., 2022), highlighting the clinical relevance of assessing psychological change over time. UK cleft services provide routine clinical psychology input at key stages of the orthognathic pathway, enabling systematic collection of pre- and post-operative outcome measures. This analysis compares psychological and quality-of-life outcomes before and after orthognathic treatment in a single UK cleft centre.

Aims & Objectives: To evaluate psychological and quality-of-life outcomes following orthognathic treatment in a single UK cleft service.

Methods: Patient-reported outcome measures were collected at decision-making (pre-orthodontics) and 12 months post-surgery as part of routine clinical psychology care. Measures included the Hospital Anxiety and Depression Scale (HADS), the Cleft Hearing, Appearance and Speech Questionnaire (CHAS-Q), and the Orthognathic Quality of Life Questionnaire (OQLQ). Pre-operative outcomes were compared with published population norms where available, and pre–post changes were analysed using paired parametric (t-tests) or non-parametric (Wilcoxon) tests.

Results/Conclusions: Sixty-two cleft lip and/or palate patients who underwent orthognathic treatment with data at decision-making and 12-month follow-up were included. At decision-making, satisfaction with facial appearance and side profile (CHAS-Q) was substantially lower than normative values, particularly in males, while whole appearance scores were closer to population norms; anxiety and depression were broadly comparable to normative samples.

At 12 months post-surgery, levels of anxiety and depression remained comparable to, or better than, general population levels. Appearance satisfaction increased significantly across multiple CHAS-Q domains, including facial and whole appearance, side profile, and perceived cleft noticeability. Orthognathic quality of life scores improved significantly, indicating reduced appearance-related and functional distress.

Psychological Determinants of Aesthetic Concern in Cleft Care: Implications for Restorative Services

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Background / Introduction: Cleft lip and/or palate (CLP) is associated with long-term functional, aesthetic and psychosocial challenges. While surgical and orthodontic outcomes are routinely measured, patient-reported quality of life (QoL) and psychological wellbeing are less consistently embedded into cleft service evaluation within restorative dentistry which is often provided in dental teaching hospitals. Evidence from facial difference literature suggests that visible dental and facial features have disproportionate psychological salience, influencing social participation and care-seeking behaviour.

Aims & Objectives: To examine presenting complaints within a regional cleft restorative cohort, interpret these findings through established psychological frameworks, and explore implications for restorative workforce planning and multidisciplinary team (MDT) service design at a national level.

Methods: A retrospective service evaluation of restorative referrals within a regional cleft service was undertaken. Presenting complaints were categorised by a primary driver. Findings were interpreted using psychological models and contextualised with contemporary cleft quality-of-life literature and UK outcome reporting standards.

Results / Conclusions: Dental aesthetic concern was the most frequently reported presenting complaint. This pattern is consistent with psychological literature demonstrating the central role of facial and dental appearance in identity, self-esteem and social functioning, particularly during adolescence and adulthood. These findings suggest that attendance can be driven by cumulative psychosocial burden rather than functional deficit alone. Routine integration of patient-reported outcome measures (PROMs) would allow services to capture meaningful psychological and social outcomes. Psychology-informed restorative planning, delivered at predictable points within the cleft pathway, may improve patient-centred outcomes and MDT efficiency. These findings have implications for the development of key performance indicators for restorative dentistry in the provision of care for cleft patients.

"It's a Two-Way Street": Parent Experience and Engagement through Animation

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Introduction: The HANDCLAP study explored parent experiences of accessing primary dental care for children with a cleft. Parents reported multiple barriers like communication, long waiting times, and uncertainty around pathways, influenced by factors such as language, socio-economic circumstances and parental priorities. Qualitative interviews captured these experiences well, written outputs alone may not be accessible to all families, highlighting the need for diverse outputs to support parent engagement.

Aims & Objectives: This project aims to make HANDCLAP findings easy to understand and accessible, using co-produced, visual methods for parent experience and engagement to reduce language and literacy barriers.

Methods: The animation title, It's a Two-Way Street, was suggested by a parent. Graphic drawings developed during parent sessions were adapted into storyboards and animated using a speedy drawing technique, with images revealed in real time to keep information simple. Music for the animation was composed voluntarily by a group of doctors as part of a charitable contribution. Feedback from stakeholders led to further improvements including the use of QR codes to help parents in finding a dentist. Animation production was funded by a children's charity.

Results / Conclusions: The project produced a 1.5-minute animated film with strong visuals and no voiceover, supporting understanding across different language backgrounds. Street signs and symbols were used to reflect common dental care experiences.
The animation will share information on why children should have regular dental checks, barriers to access care and what parents can do, if they do not have access. While designed to support understanding and engagement, its impact on parental behaviour and access to care is yet to be evaluated. This work will be shared online, including CLAPA and offers a practical model for inclusive dissemination beyond journal publications and conference presentations.

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Can it be assumed that children with speech difficulties welcome speech therapy? An ethical perspective

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Abstract

Background: This presentation recognises that children with speech sound disorders in the cleft palate population may not be consciously aware of their speech 'inaccuracies'. They may have no innate desire to change the way they talk and may be confused by therapy to help them to improve their speech. In the interests of prioritising child well-being, the risk that well-intentioned therapy could be emotionally harmful, warrants attention.

Aims and objectives: We explore the child perspective of their own speech, and of therapy which requires them to replace their existing sound productions with new sounds, sounds which may not feel, or sound, 'right' to them. The risk that therapy to change a child's speech might cause confusion, fear of failure, and emotional distress is explored in the context of ethical principles. Strategies to minimise these risks are proposed.

Method: Review of clinical video data and adult reports of childhood experiences in therapy are considered in the context of relevant child development literature and ethical principles of beneficence, non-beneficence, resilience, and autonomy.

Results: Both observational child video data and adult reflections on childhood therapy revealed varying degrees of unease about therapy. Child videos showed signs of fear of failure and confusion whereas two of the three adult reflections included prolonged, suppressed distress and anger about their childhood therapy.

Conclusion: In seeking to 'do good', therapy for child speech disorders should also prioritise emotional well-being by exploring and engaging with the child's own perspective of their speech. Strategies are suggested for ensuring that therapy is child-focussed, that it promotes autonomy and positive self-esteem, and minimises the risk of 'failure' or negative experiences which may cause imperceptible, emotional harm.

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Accessing Cleft Care in Adulthood: Patient's Experience of Pre-Appointment Clinical Psychology Consultations at ELCS

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Introduction: The Evelina London Cleft Service (ELCS) provides lifespan care for individuals born with cleft lip and/or palate (CL/P) across South East England. In the UK, individuals born with cleft typically receive treatment throughout childhood and adolescence before being discharged aged 20. However, around 45% of individuals born with CL/P in the UK seek treatment for issues related to their cleft in adulthood (Kapen et al., 2019; Sinko et al., 2005). Studies suggest desire for further treatment may be linked to dissatisfaction with appearance, psychological distress, and/or symptoms of anxiety and depression (Bemmels et al., 2013; Chuo et al., 2008).

In response to this, alongside other cleft services across the UK, the ELCS has developed a protocol for all new and returning adult patients to be offered an initial psychology consultation, prior to their main MDT (multi-disciplinary team) appointment. This primarily aims to explore patient expectations and identify psychological needs, however also provides a clearer understanding of the patient's treatment history and current priorities.

Aims: This study aims to explore the experiences of adults referred to the ELCS. It aims to explore perceptions of the referral process, the new adult psychology consultation, and the impact of psychological input on their experience of the MDT clinic and onward treatment decisions.

Methods: Ten self-selecting ELCS adult patients, with previous experience of this pathway, were asked to participate in semi-structured interviews. Inductive thematic analysis was used to identify key themes and subthemes, and examined in relation to existing research.

Results and Conclusions: Overall, feedback was positive with patients reporting appointments created a dedicated safe space for clarification of their hopes and expectations when returning to cleft services as adults. Four key themes were identified: Holistic Care, Navigating the System, Empowerment, and Accessibility. Clinical implications and limitations are discussed.

A Review of Termination of Pregnancy (TOP) with Cleft Lip (CL) and/or Palate (CL/P) Diagnosis

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Background: Antenatal detection of cleft lip and/or palate (CL/P) remains challenging. Isolated cleft palate cannot be reliably identified on ultrasound, meaning counselling is often based on suspected cleft lip alone. Under Section 1(1)(d) of the Abortion Act 1967 ("Ground E"), termination of pregnancy (TOP) is permitted at any gestation for foetal abnormality; however, neither "substantial risk" nor "severe handicap" are legally defined. In 2020, a bill proposing to exclude CL/P from qualifying abnormalities under Ground E was introduced but did not progress. An eight-year study in 2001 found antenatal cleft severity was inaccurate in 38% of cases. A 2013 Eurocat review suggested significant national under-reporting, estimating 157 CL/P-related terminations between 2006–2010, compared with 14 officially reported. Advances in UK cleft care over the past 30 years emphasise the need to re-evaluate legislation and counselling practice.

Aim: To explore the incidence of TOP following antenatal diagnosis of CL/P.

Methods: A retrospective review of antenatal referrals to the specialist cleft nursing team between 2023–2025 was undertaken.

Results: Seventy-five antenatal referrals were identified, of which 7% resulted in TOP. Antenatal diagnosis was inaccurate in 23% of cases, including infants born without a cleft. National government data indicate a rising number of TOPs associated with CL/P both before and after 24 weeks gestation. Six terminations beyond 24 weeks were recorded in both 2021 and 2022, compared with one in 2018.

Conclusion: Termination following antenatal diagnosis of CL/P continues despite improving outcomes and advances in care. A significant proportion of antenatal diagnoses remain inaccurate, reinforcing the importance of high-quality, balanced counselling. Mandatory referral of all suspected antenatal cases to specialist cleft teams should be recommended. Ongoing collaboration with the Cleft Lip and Palate Association and local fetal medicine teams aims to improve national guidance and sonographer support.

Lip Filler in Cleft Care: Patient-Reported Psychological Impact and Implications for a Standardised Cleft Pathway

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Background: Aesthetic adjuncts such as lip filler are increasingly requested by adults with cleft lip and palate, yet patient reported psychological outcomes and service delivery models remain under described in cleft pathways. Building on staff perceptions presented at CFSGBI 2024, we evaluated service user experiences to inform whether and how filler should sit within a psychologically informed, standardised cleft-care pathway.

Aims: This evaluation aimed to:

- Explore service users' experiences of lip filler delivered within a specialist cleft service.

- Examine perceived psychological and aesthetic outcomes
- Assess the acceptability and value of providing lip filler within cleft services
- Identify key factors for safe and effective delivery, with particular focus on expectation management and psychological considerations
- Inform development of a standardised, psychologically-informed pathway for lip filler intervention in adult cleft

Method: Purposive sample of individuals who had received lip filler via the Welsh Centre for Cleft Lip and Palate. A patient survey was sent to all eligible patients at the time of data collection; 21/32 responded. Quantitative items were summarised descriptively; open ended responses underwent thematic analysis at the item level.

Results and Conclusions:

- Universal positive overall experience despite initial hesitation.
- Reported improvements in symmetry, balance and fullness, associated with greater happiness and confidence.
- Provision within cleft services was viewed as important to patients.
- Expectation management emerged as a priority for safe, acceptable delivery.
- Illustrative quotations highlight mechanisms of benefit and areas of unmet need.

In conclusion, lip filler, delivered within a standardised cleft service, can address both physical and psychological needs for some patients. Findings support:

1. embedding pre-procedure psychological screening and expectation setting,
2. developing clear referral and follow up pathways within cleft services, and
3. co producing a dedicated clinical pathway with service users to clarify indications, risks and supports.

How engaging with CLAPA and Cleft Development Group Patient Engagement Group improved CRANE patient resources

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Background/Introduction: CRANE patient-public leaflets were updated or newly prepared following feedback received during the Confidentiality Advisory Group (CAG) Section 251 approval process. To meet approval requirements, suggested changes were implemented, and a review was conducted in partnership with CLAPA & the Cleft Development Group (CDG) Patient Engagement Group (PEG) to ensure transparency and ethical governance.

Aims & Objectives: To gather patient/patient representative views on:

- Use of confidential patient information without explicit consent
- Retention of NHS numbers for individuals who decline participation
- Clarity, tone, and accessibility of revised patient materials

Methods: Draft materials, including the combined information leaflet, consent form, and supporting documents, were shared with CLAPA's Involvement Manager and CDG PEG members. Feedback was collected through written review and group discussion.

Results/Conclusions: CDG PEG Patient representatives welcomed CRANE's transparency and purpose, finding the content informative and reassuring. Key recommendations included:

- Simplifying language and improving clarity
- Highlighting CRANE's role in improving cleft care and safeguarding data
- Consolidating two lengthy leaflets into a single, streamlined version
- Adding links for further information and revising terminology

The revised leaflet now combines previous documents into a concise, user-friendly format, improving accessibility for families. Feedback will be formally submitted to CAG via CRANE and incorporated into future engagement strategies to ensure meaningful public involvement. This case study demonstrates that involving CLAPA and CDG PEG can significantly enhance patient resources and experience.

The CDG PEG is available to all cleft teams and CEN's as a resource to provide patient perspectives, feedback and ideas ensuring that patient resources and new initiatives are co-designed by those who use them to improve relevance and overall patient experience.

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Guidance for CAG applicants, NHS Health Research Authority, 2024

Using Plain Language in Health Information, Patient Information Forum, 2024

Building Community Through Research: Young People's Involvement in the Cleft@18–23 Project

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Background: Growing up with a cleft lip and/or palate often means spending many years in children's clinics and building close relationships with healthcare teaMs When care moves into adult services, this support can suddenly feel very different. For many young people, this transition comes with a sense of loss and feeling less connected, which shaped our journey into becoming involved in research. Individuals with lived experience of cleft have been engaged in the Cleft @18-23 study as co-applicants, members of the Patient and Public Involvement (PPI) group and representatives of the community throughout the research process.

Aim: To report the process and impact of engagement with research as members of the Cleft@18–23 PPI group.

What we have done: Integral to the research process, individuals with lived experience of cleft have taken part in surveys and focus groups, which developed the research questions, designed the logo and strap line for the study, helped shape the look and feel of the project, supported recruitment, and used social media to reach others with cleft.

Impact: The involvement of young people born with cleft in the development and running of this study has increased visibility, helped people feel represented, and encouraged connection with others who share similar experiences. It will generate richer data that more accurately reflects real-world transition experiences.

We hope to continue building a supportive community and to see future research shaped and led by people with lived experience.

Developing an Enhanced Recovery Pathway for Primary Cleft Palate Surgery: A National Multi-Centre Study

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Background: Peri-operative pain management following cleft palate surgery varies widely, with limited cleft-specific guidance to inform best practice. Variability in analgesic modalities may contribute to inconsistent pain control and delayed functional recovery. Enhanced recovery pathways have improved outcomes in other paediatric surgical cohorts but are not well established in cleft palate surgery.

Aims & Objectives: To create a consensus-informed enhanced recovery pathway for cleft palate surgery, with a focus on optimisation of the patient and parent journey within cleft care.

Methods: A retrospective, multi-centre review was conducted across twelve UK cleft centres, surveying their management of peri-operative pain for cleft palate surgery. Data was collected on operative approach, general anaesthetic, intra-operative adjuncts, post operative analgesic protocols, operation length, length of stay and time to first feed.

Results: Intra-velar veloplasty is the surgery of choice with a gas induction although 1 centre uses total intravenous anaesthesia (TIVA). All centres infiltrate the palate with local anaesthetic +/- adrenaline. 4 centres use supra-zygomatic maxillary nerve blocks, 2 centres use infraorbital nerve blocks. Paracetamol, morphine and fentanyl were the most common intra-operative adjuncts. Paracetamol, NSAIDs & oramorph feature regularly in post operative analgesic plans, with 3 centres utilising benzydamine hydrochloride (Difflam) spray. Operative time of 90-120mins, 1 day stay and 30-60mins to first feed were the most frequent data points.

Conclusion: Significant variability exists in peri-operative pain management following cleft palate surgery in the UK. Areas of convergence and variability were identified to inform a standardised enhanced recovery pathway focused on multimodal analgesia and early functional recovery. This pathway can provide a practical framework for local implementation and quality improvement in cleft patient care.

Reversal of cleft speech in a transgender patient undergoing testosterone therapy: a case report

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Background: In the transgender population, voice correlation with their experienced gender has been reported to enhance quality of life, promote better life satisfaction, and reduce mental illness in the form of depression and anxiety. Testosterone therapy in female-to-male transgender patients is understood to affect the frequency of vocal fold vibration which determines voice pitch, and structure of speech formants which reflect vocal tract length.

Aims & Objectives: We present a case of a female cleft patient with a previous history of unilateral cleft lip and palate repair, who presented aged 17y with evidence of velopharyngeal insufficiency (VPI) and nasal emission during speech.

Method: The patient was listed for secondary speech surgery in the form of posterior pharyngeal wall augmentation with injection; however prior to undergoing this surgery, the patient commenced Testosterone therapy for gender reassignment purposes.

Results: On follow up post testosterone therapy, the patient's voice was notably deeper pitched, and on speech assessment there was no longer evidence of VPI, nor nasal emission. Surgery was therefore no longer necessary.

Conclusions: To our knowledge, this is the first documented case of cleft speech being reversed due to Testosterone therapy, and suggests further research into the effect on the pharynx is warranted.

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Significant regional variation in timely detection of clefts is holding back national improvement

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Background: Early diagnosis of cleft lip and/or cleft palate enables timely referral to specialist services. National benchmarks recommend antenatal detection for clefts involving the lip and diagnosis within 24–72 hours of birth for cleft palate only (CPO). Despite established screening pathways, national progress appears to have plateaued. This study evaluates recent UK performance and regional variation in timely cleft detection.

Methods: Children registered in the CRANE Database and born 2022-2024 were classified by cleft type and timing of diagnosis. Timely detection was defined as antenatal diagnosis for cleft lip with or without cleft palate (CL±CP), and diagnosis antenatally or within 24 or 72 hours of birth for CPO. Children with submucous cleft palate and those born before 34 weeks' gestation were excluded from CPO analyses. Timely detection rates were calculated for each regional cleft service. Logistic regression was used to generate adjusted rates: CL±CP models adjusted for laterality, completeness of lip involvement, and sex; CPO models adjusted for extent of palate involvement, syndrome status, and sex. Funnel plots compared service performance with national averages and detected statistical outliers.

Results: Among 1,418 children with CL±CP, 78.3% were diagnosed antenatally. Adjusted regional detection rates varied considerably, ranging from 51% to 93%. Among 1,046 children with CPO, 74.7% were diagnosed within 24 hours and 85.1% within 72 hours. Substantial regional variation persisted after adjustment (61%–82% for 24-hour detection and 70%–93% for 72-hour detection). Cleft completeness was a significant predictor of timely detection for both CL±CP and CPO.

Conclusion: Timely detection of cleft lip and cleft palate in the UK remains highly variable, with regional inconsistency limiting national improvement. Strengthened screening governance, targeted support and education for under-performing regions, and consistent implementation of best practice across maternity and neonatal services are needed to reduce unwarranted variation and improve early cleft detection.

Inter- and Intra-Rater Reliability of LAHSHAL and LAHSAL Classification Systems for Cleft Lip and Palate

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Background/Aims: As understanding of the genetic and embryological origins of orofacial clefts advances, detailed phenotypic classification becomes increasingly important for genotype-phenotype research and outcome comparisons. LAHSHAL provides more anatomical detail than LAHSAL, but has not been formally validated. Recent work comparing the CRANE and Cleft Collective databases showed phenotype agreement deteriorates with increasing classification complexity (LAHSAL agreement=47.2%, Krippendorff's α=0.32). This study aimed to determine the intra-rater reliability and accuracy of LAHSHAL compared to LAHSAL.

Methods: An expert consensus panel (cleft surgeons and orthodontist) established gold-standard codes for 100 clinical photographs of patients with cleft lip+/-palate. Nineteen assessors (7 specialist nurses, 4 orthodontists, 8 surgeons) independently coded images using both systeMs Eleven assessors repeated the exercise to enable intra-rater reliability analysis. Accuracy was calculated as proportion of codes matching the gold standard. Intra-rater reliability was assessed using observed agreement (Po), Cohen's kappa, and Gwet's AC1.

Results: Round 1 accuracy was 60.1% (SD=12.9%) for LAHSHAL and 69.3% (SD=8.9%) for LAHSAL. Mean observed agreement was 73.5% (SD=9.5%) for LAHSHAL and 78.6% (SD=6.8%) for LAHSAL. Cohen's kappa demonstrated substantial-to-almost-perfect reliability: κ=0.714 (SD=0.100) for LAHSHAL and 0.765 (SD=0.076) for LAHSAL. Gwet's AC1 values were similar (LAHSHAL=0.727, LAHSAL=0.779), confirming result stability. Cleft surgeons achieved 'almost-perfect' consistency (κ>0.82 both systems), specialist nurses 'substantial agreement' (κ=0.71-0.76), and orthodontists 'moderate-to-substantial agreement' (κ=0.61-0.71). Surgeons demonstrated highest accuracy (LAHSHAL=67.6%, LAHSAL=75.9%).

Conclusions: Both systems demonstrate good intra-rater reliability across professional groups. While LAHSAL showed slightly higher reliability and accuracy overall, LAHSHAL maintained good performance despite encoding more phenotypic detail. Surgeons achieved almost perfect consistency with LAHSHAL, suggesting that with appropriate training and calibration, detailed phenotypic coding can be reliably performed. We recommend that coding be undertaken using the LAHSHAL system at the time of primary surgical repair by the treating cleft surgeon, supported by calibration training to optimise coding accuracy and consistency.

Folic Acid Supplementation and Orofacial Clefts: Evidence Supporting Updated NICE Guidance

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Background: Orofacial clefts, including cleft lip with or without cleft palate (CL±P) and isolated cleft palate (CP), are common congenital anomalies with a multifactorial aetiology. Folic acid supplementation is well-established in the prevention of neural tube defects; however, its role in preventing orofacial clefts remains unclear. In 2024-25, NICE updated its maternal nutrition guidance, reaffirming routine periconceptional folic acid supplementation and recommending higher doses for pregnancies at higher risk of developing congenital anomalies. This update warrants review to determine whether current evidence supports these recommendations in relation to orofacial clefts.

Aims & Objectives: To review and synthesise existing evidence on folic acid supplementation for primary and secondary prevention of orofacial clefts, and assess whether evidence supports implementation of this recent NICE guideline update.

Methods: An evidence-based overview was conducted using data from observational studies, meta-analyses, randomised and high-dose pregnancy risk reduction trials, ecological studies of food fortification, and national surveillance reports. NICE evidence reviews and guideline recommendations were incorporated to contextualise findings.

Results: Observational studies and meta-analyses demonstrate a consistent association between periconceptional folic acid use and reduced risk of CL±P, with pooled estimates suggesting approximately 40% relative risk reduction. Evidence for isolated CP is weaker and less consistent. Randomised and high-dose studies indicate a potential reduction in risk of subsequent pregnancies developing orofacial clefts, particularly CL±P, among women with a previously affected pregnancy, with no significant safety concerns reported.

Conclusions: Although limitations include residual confounding and heterogeneity across cleft subtypes, the balance of evidence supports routine 400 µg/day folic acid supplementation for the general population and higher doses (5 mg/day) for women at higher risk, in line with updated NICE guidance.

Declining Birth Rates and Cleft Surgery Training: A 25-Year National Analysis of Case Volume Trends

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Background or Introduction: Cleft lip and/or palate requires specialist surgical expertise within centralised multidisciplinary services. UK birth rates have declined substantially since 2012, raising concerns about reduced surgical case volumes and implications for training and service sustainability. The CSAG recommendations emphasise maintaining adequate surgeon case volumes to ensure quality outcomes.

Aims and Objectives: To examine temporal trends in UK cleft cases and incidence rates from 2000-2024, and assess implications for surgical training capacity.

Methods: Annual UK live births (2000-2024) were obtained from Office for National Statistics data. Cleft cases were extracted from CRANE registry reports. Cleft incidence per 10,000 live births was calculated. Temporal trends in absolute case numbers, birth rates, and incidence were analysed descriptively.

Results: UK live births declined 18.5% from the 2012 peak (729,674) to 2024 (594,677). Total cleft cases fell 22.9% from the 2012 peak (1,168 cases) to 2024 (901 cases). The 25-year mean was 958 cases annually. Cleft incidence rates fluctuated between 11.89 and 16.71 per 10,000 births, with no clear downward trend (2012: 16.01; 2024: 15.15 per 10,000). Despite stable incidence rates, absolute case numbers have declined proportionally with falling birth rates.

Conclusions: While cleft incidence remains stable, absolute case volumes have declined by nearly one-quarter from peak levels, mirroring reduced birth rates. This represents a significant reduction in training opportunities and may challenge maintenance of the CSAG-recommended case volumes per surgeon. National workforce planning must address these demographic shifts to ensure sustainable specialist training and service delivery.

The NHS is changing. How will it affect Cleft services?

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Introduction: Health systems across the UK are undergoing significant change. In England, reforms to NHS structures and commissioning, including the future role of NHS England, raise important questions for specialised services such as cleft care. The devolved nations also operate distinct commissioning models shaped by different policy priorities. For services that rely on national coordination and consistent standards, understanding how these changes may affect delivery is increasingly important.

Aims & Objectives: This session aims to explain the emerging commissioning landscape for cleft services across the UK, with a focus on changes underway in England. It will outline how reforms may affect accountability, consistency, and service stability, and highlight key issues cleft teams may wish to consider as systems evolve.

Methods: The session draws on policy analysis, engagement with national and devolved policymakers, and input from the Specialised Healthcare Alliance on specialised commissioning in England. CLAPA is engaging with system leaders, clinicians, and partner organisations to understand the reforms and their potential impact. This work is informed by discussions with cleft teams, charities, and professional bodies across all four nations. As reforms continue to develop, content will reflect the most up-to-date position at the time of the conference.

Results / Conclusions: Early indications suggest commissioning reforms could affect how cleft services are planned, funded, and overseen, particularly where national consistency and specialist expertise are needed. Divergence between UK systems may increase, especially with devolved elections shortly after the conference in May 2026.

This session will outline the direction of travel, areas of uncertainty, and practical questions for cleft teaMs CLAPA will also explain how it is engaging nationally to represent patient interests and support services through change. The aim is to help ensure reform does not undermine equitable, high-quality cleft care and turn them into an opportunity to improve care.

Clinical Psychology in the Planning of Cleft Rhinoplasty: Our Experience of Establishing a Pre-Surgery Psychology Pathway in the Evelina London Cleft Service

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Introduction: Patients born with a cleft lip and/or palate (CL/P) in the UK often undergo rhinoplasty once their growth is complete to address aesthetic and/or functional differences, such as a deviated septum or underdeveloped nasal cartilage. Research shows high satisfaction after secondary rhinoplasty (Homsy, Grann & Lassus, 2024), however surgery can provoke psychological distress if expectations are unmet (Kappen et al, 2019). Growing consensus emphasizes the need for psychological support before and after surgery to understand motivations, ensure informed consent, and manage expectations (Nuffield Council on Bioethics, 2017). This is particularly relevant for the cleft population (Ardouin et al, 2020).

Aims: To share reflections on formalizing a clinical psychology pathway for all CL/P patients under the Evelina London Cleft Service who are seeking rhinoplasty surgery.

Methods: This study reports on our process of piloting a pathway where all patients considering rhinoplasty meet with a Clinical Psychologist before surgery to discuss hopes and expectations, review psychological readiness for surgery and any need for support. Standardized questionnaires are given at the decision-making stage and 12-month post-operative review. These include measures of appearance satisfaction (FACE-Q, CLEFT-Q, Rhinoplasty Outcome Evaluation), psychological wellbeing (PHQ-9, GAD-7), and self-esteem (Rosenberg Self-Esteem). Qualitative feedback from patients and surgeons on their experience with this pathway is also being collected.

Results: We will report on the early experiences of this pathway's implementation, findings from questionnaire data and qualitative feedback. We hope to have piloted this pathway with 30-40 patients by April 2026.

Conclusion: The results will help to guide the development of this pathway further with the expectation that it will become standard practice across cleft teams nationally and internationally. This pilot study will highlight the importance of including psychological assessment and support for cleft patients considering rhinoplasty.

Missed at Birth: Are Cleft Palates Overlooked Due to Gaps in Newborn Screening Guidelines?

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Background: Missed diagnoses of cleft palate (CP) can lead to significant neonatal morbidity, including feeding difficulties, poor growth, and aspiration pneumonia. Despite this, CP is still frequently missed at birth worldwide. This is often not due to clinical oversight, but to unclear newborn screening (NBS) guidance. Without practical instructions, healthcare workers—particularly in resource-limited settings—may rely on experience alone, resulting in missed opportunities for early diagnosis.

Objectives: To assess the extent, clarity, and consistency of CP screening recommendations in national and international NBS guidelines, and to identify gaps that may contribute to missed diagnoses.

Methods: We searched PubMed, Google Scholar, national and international organisations, and grey literature for English-language NBS and CP-specific guidelines. Extracted data included country, timing of newborn examination, designated examiner, mention of CP, distinction between CP and cleft lip (CL), examination method, and reference to uvula visualisation.

Results: Fifteen NBS guidelines from eleven countries were identified. Although most mentioned CP, over half did not distinguish CP—which requires intra-oral examination—from CL, which is externally visible. Among guidelines that recommended intra-oral examination, most failed to specify which anatomical structures should be examined. Only one guideline explicitly mentioned uvula inspection, a key step in detecting submucosal cleft palate.

Conclusion: Inconsistent terminology and vague screening instructions increase the risk of delayed or missed CP diagnoses, with potentially lifelong consequences. Standardised NBS protocols that clearly define examination methods, tools, and CP–CL distinctions are essential to support early detection and reduce preventable neonatal morbidity.

A Practical Approach to Collaborative Cleft Care Between the UK and Nepal

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Background: Collaborative cleft work across different healthcare systems can be challenging. Differences in governance, resources, data collection and patient expectations often limit collaborative work, and direct comparison of outcomes is not always appropriate or helpful.

Aim: To describe a practical approach to collaborative cleft care projects between Nepal and the UK, that recognises the individuality of healthcare systems and supports shared learning and service improvement.

Methods: Since 2022, cleft teams at Kirtipur Hospital, Nepal and UK centres in Liverpool, Newcastle, and London have worked together through reciprocal multidisciplinary visits and regular virtual meetings, supported by the charity CLEFT – Bridging the Gap. The collaboration included funding of a cleft fellow in Nepal to support clinical activity and outreach service delivery. A shared approach to collaboration in audit and research was agreed, covering governance, multidisciplinary involvement, and locally appropriate data collection, with projects approved locally as audit, service evaluation, or research.

Results: This approach enabled delivery of several collaborative projects relevant to both healthcare systeMs The first focused on Alveolar Bone Grafting and established shared ways of working without direct outcome comparison. Currently in progress is DENTSPASS, a nurse-led programme integrating speech therapy, oral hygiene education and motivational support and a further project which is a speech- and psychology-led initiative for developmental assessment of children in the early years. In addition, the collaboration has extended beyond clinical projects, with members of the UK team engaging with the Liverpool Nepali community and plans for local fundraising to support cleft care for children in Nepal.

Conclusion: This work describes a simple, workable approach to collaborative cleft care across different healthcare settings. By recognising the individuality of healthcare systems and focusing on shared processes rather than comparison, it supports meaningful collaboration and quality improvement.

Exploring Sustainable Development Goal integration in orofacial cleft research: Insights from a comprehensive coded dataset

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Introduction: Annually, over 8 million newborns are affected by orofacial clefts(OFCs), making these some of the most common congenital conditions. Their lifelong impact requires multidisciplinary approaches. In 2010, the World Health Organisation reinforced global responses to congenital conditions (WHO,2010), integrating with the United Nations Sustainable Development Goals(SDGs) for 2030 (United Nations,2016).

Aims & Objectives: This research evaluated SDG representation in OFC publications, by identifying trends in SDG mentions and understanding their thematic relevance, while assessing how these relate with country income status.

Methodology: Using a Phyton script developed by Elsevier, a comprehensive keyword search and analysis of all OFC-related articles was conducted, comprising articles written between 1842 and 2024. The script inferred SDG themes from the articles, focusing on SDG mentions, thematic relevance, and World Bank country income classification of authors' countries.

Results/Conclusion: Out of 39,176 publications, 5,598(14%) referenced at least one SDG, with 6,069 unique mentions. Changes in health and nutrition mentions were statistically significant ($p<0.0001$). SDG3-Good Health was predominantly cited (4,255 references) but decreased in frequency as country GDP decreased ($p<0.0001$). Conversely, SDG2-Nutrition mentions increased with lower GDP ($p<0.0001$). Goal 16.9, crucial for congenital registrations, was underrepresented. Partnerships became fundamental in lower GDP contexts (SDG-17), where OFC care is largely supported by Non-governmental organisations (NGOs). Educational mentions varied globally, with MDT education and outcomes for children affected by clefts being mentioned in different contexts. In low-income countries, nutrition is still a major challenge. Associations with non-human clefts, such as those in marine species, were also detected. These observations highlight the diverse OFC-related challenges and priorities globally, informing cleft-relating care, aiming to achieve the SDGs by 2030. Limitations include thematic analysis only, language restrictions, and diverse country groupings. A global effort is needed to address patients' needs through OFC care, ensuring progress toward these goals.

Embryological Training Gaps in UK Ultrasonography: Addressing Misinformation in Cleft Counselling

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Background: Orofacial clefts affect approximately 1 in 700 live births and are among the most treatable congenital conditions. Prenatal detection in the UK relies largely on the routine 20-week anomaly scan which assesses multiple foetal organ systems within a short allotted timeframe. Diagnosis remains challenging with detection rates of 78% reported to CRANE. Many ultrasonographers have limited clinical exposure to cleft cases during both training and early practice. Recent clinical encounters highlight variability in understanding of cleft embryology, terminology and prognosis, which has impacted accuracy of counselling delivered within our network.

Objectives: To review embryological content relating to orofacial clefts within UK ultrasonography curricula, identify potential areas of educational deficit, propose recommendations to strengthen training and support accurate prenatal assessment and counselling.

Methods: Programme specifications and competency frameworks from CASE-accredited ultrasonography courses were reviewed. Content was examined for coverage of facial development, primary and secondary palate formation, correlation with sonographic landmarks, and cleft counselling. Illustrative clinical scenarios were reviewed to explore implications of knowledge gaps on parental counselling.

Results: Considerable variability was identified in the depth, clarity and explicitness of cleft-related embryological content. Recurrent areas of potential deficit included differentiation between primary and secondary palate development, linkage of embryology to practical ultrasound imaging, and structured communication regarding uncertainty, prognosis and treatment pathways. Integration of cleft embryology within anomaly-scan teaching was inconsistent.

Conclusions: Strengthening cleft-related embryology within UK ultrasonography training represents a clear opportunity to improve prenatal detection and onward referral for parental counselling. We have planned a local training day in March, in collaboration with our Trust's Foetal Medicine Unit, to raise awareness amongst ultrasonographers and foetal medicine residents within our network in the hope this will help to embed cleft-related embryology within practical scanning instruction, and improve competency development with the aim of supporting informed decision-making for families.

Does Fidelity Really Matter? Educational Value of Affordable Simulation Across the Cleft Surgery Cost Spectrum

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Background: Cleft lip and palate surgery is technically demanding with a steep learning curve and limited operative exposure worldwide. Many simulators exist, but it is unclear which characteristics such as cost, fidelity and accessibility are most strongly associated with educational outcomes. Most patients live in low-and middle- income countries, where access to high-fidelity simulation is often constrained. Previous reviews have catalogued simulators, but none systematically examined which features contribute most to effective surgical training.

Aims and Objectives: To systematically review cleft surgery simulation across the full cost spectrum and identify which simulator features are most associated with educational impact, with particular focus on affordable, low-cost models relative to high-fidelity simulators.

Methods: A systematic review was conducted in accordance with PRISMA guidelines. Searches covered major databases and grey literature from inception to late 2025. Physical (high-fidelity, 3D-printed, ultra-low-cost organic), digital, virtual reality, cadaveric, and ex vivo animal models were included. Two reviewers independently screened studies, extracted data, and assessed quality. Non-surgical simulations and conference abstracts without full text were excluded. Studies were categorised by cost, fidelity, simulator type, training level, validation evidence, educational outcomes,, and global accessibility.

Results: Sixty-nine studies were included. Learner satisfaction and educational outcomes were often comparable between low-cost and high-fidelity models despite substantial cost differentials. Significant heterogeneity in outcome assessment methods and limited validated measures of predictive validity were noted. Gaps were identified in simulation for complex phenotypes and revision surgery.

Conclusion: Educational impact in cleft surgery simulation does not depend solely on cost or fidelity. Affordable, low-cost models provide meaningful learning, particularly at early training stages and in resource-limited settings. An evidence-based, resource-sensitive approach is needed to guide simulator selection and prioritise features most associated with effective surgical learning.

Genomic common variant investigation of neurodevelopmental risk in children born with cleft lip and/or palate

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Background: Children born with cleft lip and/or palate (CL/P) have elevated rates of neurodevelopmental difficulties, including ADHD and autism spectrum disorder. Previous work from our group identified that rare neurodevelopmental copy number variants (ND-CNVs) are enriched in children with CL/P and associated with poorer developmental outcomes. However, ND-CNVs are not present in most children with CL/P, raising the question of whether shared common genetic variants might contribute to these comorbidities.

Aims & Objectives: We aimed to investigate whether common genetic variation explains neurodevelopmental risk in CL/P by: 1) testing for genetic correlations between cleft and neurodevelopmental traits; 2) comparing polygenic risk scores between children with CL/P and controls; 3) examining whether polygenic scores are associated with behavioural outcomes within the cleft population; and 4) testing for causal effects using Mendelian randomization.

Methods: We analysed genetic data from 2,313 children with CL/P from the Cleft Collective and 7,913 controls from the Millennium Cohort Study. We estimated genetic correlations using linkage disequilibrium score regression and calculated polygenic risk scores for ADHD, autism, depression, anxiety, schizophrenia, bipolar disorder, educational attainment and

intelligence. Longitudinal behavioural outcomes were assessed using validated measures (SDQ, ASQ, MFQ, SCARED) at multiple timepoints.

Results/Conclusions: We found no evidence of genetic correlations between CL/P and neurodevelopmental traits. Children with CL/P did not carry elevated polygenic risk for any disorder examined compared to controls, regardless of cleft subtype. Within the cleft population, polygenic scores for ADHD and depression showed expected associations with corresponding behavioural difficulties across developmental timepoints. Mendelian randomization provided no evidence that genetic liability to cleft causally influences neurodevelopmental outcomes. These findings suggest that neurodevelopmental risk in CL/P is not attributable to shared common genetic architecture, contrasting with our previous findings for rare variants and highlighting the distinct genetic contributions of common versus rare variation.

Prevalence of palatal fistulae following primary cleft palate surgery and associated surgical and patient factors

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Background: Cleft palate fistulae are thought to be the commonest complication of primary cleft palate surgery. A connection between the nasal and oral cavities can result in nasal regurgitation and velopharyngeal dysfunction. Often children with a fistula require surgical repair to manage these symptoms, increasing the burden of care(1).

Aims & Objectives: The primary aim was to describe the proportion of children who developed a palatal fistula following primary cleft palate surgery within the Northern and Yorkshire Cleft Lip and Palate Service, and determine the associated surgical and patient factors. Secondary aims were to determine the percentage of fistulae which required repair and the success of the palatal fistula repair surgery in terms of improvement in clinical signs and/or perceptual speech assessment.

Methods: A retrospective review was conducted to identify children who underwent cleft palate +/- lip repair, between 2005 and 2025, in the Northern and Yorkshire Cleft Lip and Palate Service. Of these patients, the prevalence of post-operative palatal fistulae was recorded, as was the number of which required surgical repair. Information was extracted from departmental auditing data and electronic patient records.

Patient factors recorded included cleft type and associated genetic syndromes or comorbidities. Surgical factors included the technique performed, operating surgeon, and the age at which fistula repair was performed. Data analysis to determine the relationship between these variables and the incidence of fistulae, and the success of fistula repair were conducted.

Results / Conclusions: Over twenty years, 876 patients were identified who underwent primary cleft palate repair within the service. A palatal fistula was recorded for 179 children. We present the patient and surgical factors associated with improved outcomes in this cohort. This fistula rate is high compared to recently published literature(2). Further work to identify how we can reduce our fistula rate moving forwards is underway.

Assessing if Maternal Exposure During Pregnancy Affects the Severity of Cleft Palate

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Background / Introduction: Cleft palate, with or without cleft lip, is a common congenital anomaly with variable phenotypic severity. While genetic factors are established contributors, maternal exposures during pregnancy, including folate intake, alcohol use, smoking, substance use and body mass index (BMI), may influence cleft severity. Understanding these associations could inform targeted prenatal interventions to reduce the risk of severe cleft phenotypes.

Aims & Objectives: This study aimed to investigate whether maternal exposures at conception are associated with the severity of cleft palate (+/- cleft lip) in infants. Specifically, it sought to quantify relationships between maternal folate, alcohol, smoking, substance use, and BMI with cleft severity, accounting for maternal age, socioeconomic status and infant sex.

Methods: An observational cohort study was conducted using secondary data from The Cleft Collective. Participants included infants with cleft palate (+/- cleft lip) whose mothers completed exposure questionnaires. Cleft severity was assessed using completeness, laterality, and Veau classification. Maternal exposures included folate intake, alcohol use, smoking, substance use, and BMI. Logistic and linear regression models were used, adjusting for maternal age, sex and household income.

Results / Conclusions: Preliminary analyses suggest increased maternal alcohol consumption and smoking are associated with increased odds of more severe clefts, while maternal BMI and substance use showed no evidence of an association. Higher maternal folate intake appeared to modestly reduce cleft severity. Male infants consistently exhibited higher odds of severe phenotypes. These findings support existing evidence that modifiable maternal exposures may influence cleft severity and highlight the need for further research to understand causal pathways

Learning Through Collaboration: Review of Alveolar Bone Grafting in the UK and Nepal

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Background / Introduction: Alveolar bone grafting (ABG) is a key timepoint in the cleft care pathway. Successful outcomes rely on multiple factors including oral health and service organisation. Barriers to delivering comprehensive care include financial limitations and absence of a multidisciplinary team. Collaborative working across diverse healthcare settings can support shared learning and improve outcomes, regardless of geographic or resource differences.

Aims & Objectives: To evaluate socioeconomic factors, care delivery and outcomes for patients undergoing ABG in the UK and Nepal and develop a practical roadmap for improvement.

Methods: Retrospective review of the records of patients who underwent ABG from 2022-2024. The project was developed by the teams during visits to Nepal and refined through virtual meetings. Five topics of interest were agreed: access to care; treatment pathway; pre-operative preparation; the ABG procedure; and post-operative outcomes and documentation. Findings were defined as successes and/or challenges using colour-coded summaries. Ethical approval was obtained in Nepal. UK data was collected in accordance with NHS audit governance.

Results / Conclusions: 220 patient records assessed (Nepal n=101; Liverpool n=55; Newcastle n=64). Collaboration between teams proved invaluable in understanding the nuances of each centre's patient cohort, treatment pathway and data management. Direct numerical comparison was avoided due to variation in sample sizes, context, funding. Data was analysed at local level rather than compared between units. This approach supported reflective practice and led to distinct, practical service changes. In Nepal, review highlighted the need for improved documentation, stronger pre-operative oral health input, and earlier recall for ABG. In the UK centres, gaps were identified in recording oral hygiene, parent satisfaction, and retrieval of records from outreach centres for assessing outcomes.

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Speech and Language Outcomes in Children with Cleft Palate Requiring Tracheostomy

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Introduction: A proportion of children within cleft services require tracheostomy for airway management, most commonly due to Pierre Robin Sequence (PRS), characterised by micrognathia, glossoptosis, and upper airway obstruction. The presence of a tracheostomy may influence both the timing of palatal repair and subsequent speech and language development, yet service-level outcome data for this complex subgroup within UK cleft services remain limited.

Aims: The primary aim of this service evaluation was to assess speech and language outcomes in children with cleft palate and tracheostomy, the majority of whom had PRS. Secondary objectives were to determine whether tracheostomy impacted the timing of primary palatal repair.

Methods: A retrospective service evaluation was undertaken using clinical records of patients treated at Royal Manchester Children's Hospital between 2011 and 2024. Children with cleft palate and a history of tracheostomy were included. 27 patients met the inclusion criteria. Data collected included cleft characteristics, PRS diagnosis, tracheostomy timing, age at primary palatal repair, and speech and language outcomes.

Results and Conclusion: PRS-related upper airway obstruction was the indication for tracheostomy in 66.7% of patients. 72% had undergone or had a plan for primary palatal repair; the remainder had co-morbidities and developmental delay precluding surgery. The mean age at palatal repair was 15 months, with 59% meeting the cleft Specialist Services Quality Dashboard standard of palate repair before age 13 months. 100% demonstrated delayed speech and language development at 18 months. At 3 years, 25% were pre-verbal, 41.7% demonstrated cleft speech characteristics and 33.3% had intelligible speech within normal limits. Speaking valves were trialled in 56.2% of patients; sustained use was achieved in 18.8%.
Children with cleft palate requiring tracheostomy demonstrate significant early speech and language delay with variable outcomes despite timely surgery. Limited access to outpatient speaking valve trials may further influence early communication development.

Autologous dermal fat grafting for secondary cleft lip revision: a single centre case series.

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Background: Secondary deformity following cleft lip repair commonly includes volume deficiency, contour irregularity and scar related distortion of the upper lip and perioral subunits. Autologous dermal fat grating offers structural soft tissue augmentation that can be incorporated alongside minor scar revision procedures. The indications and aesthetic outcomes following autologous dermal fat grating performed within a tertiary cleft service by a single surgeon are evaluated.

Methods: A retrospective analysis of consecutive patients undergoing autologous dermal fat grafting for cleft related secondary lip deformity between 2016 and 2025 was undertaken. Procedures were performed within a single tertiary unit by the same Consultant Cleft surgeon. Demographic data, concurrent operative procedures and post-operative complications were extracted from a prospectively maintained clinical database. The pre- and post-operative aesthetic appearance of the lip in repose was analysed by a panel of cleft clinicians using an Asher-McDade technique.

Results: Twenty-five patients underwent dermal fat grafting (mean age 26.0 ± 7.7 years; range 17.1–49.8 years). Sixteen patients were female (64%). Concomitant procedures were performed in 16 patients (64%) - most commonly scar revision of the upper lip mucosa with Z-plasty (8 cases; 32%) and multiple V-Y plasties of the upper labial sulcus (3 cases; 12%).

Complications were recorded in 3 cases (12%). These included two instances of graft exposure, both managed conservatively (8%), and one sterile stitch abscess of the lip (4%). No major infective complications or reoperations were observed in this series.

Conclusion: Dermal fat grafting is a promising technique for cleft lip revision that can be safely integrated with minor scar revision procedures. The technique has lasting long term results. Low donor site morbidity with minimal post-operative complications were noted in this series, thus supporting its role as a practical option for improving lip volume and contour in this patient cohort

Does phonological awareness in children with cleft lip and palate matter?

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Background: Phonological awareness (PA) is our knowledge of how words are made of syllables and sounds (phonemes). It develops in childhood and is essential for speech, language and literacy development. Awareness of larger units (syllables) develops before smaller units (phonemes). We have little understanding of the development of these skills in children born with cleft lip and palate (CLP) despite the high risks of speech and language difficulties.

Aims: This study aimed to discover if children with CLP followed the same developmental pattern and had equivalent PA skills as typically developing children; and how these relate to their speech and language development.

Method: Participants, recruited from the Cleft Language and Auditory Skills (CLAS) study, included children with all non-syndromic diagnoses of CLP who had completed a PA assessment (n=70; age 5;0-7;11 years). PA skills at syllable and phoneme level were measured. Relationships between PA scores and speech and language outcomes and group differences between children with typically developing speech, with cleft speech characteristics (CSC) and with developmental speech characteristics (DSC) were explored.

Results: 28% of children had established syllable level skills compared with 15% at phoneme level. Positive correlations were found between PA and speech production (weak), and PA and language skills (moderate). Children with DSC had poorer phonological awareness skills than those with typical speech or CSC only.
Conclusions

PA skills of children with CLP are lower than expected for their age, being similar to non-CLP children with DSC. Few of these children are identified and provided with intervention in the way non-CLP children with DSC are. Research is needed to ascertain if early PA intervention improves speech and language outcomes in children with CLP as it does for non-CLP children with DSC.

Algorithm-guided combined Furlow palatoplasty and pharyngeal flap for velopharyngeal dysfunction

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Background: Secondary speech surgery for cleft related velopharyngeal dysfunction (VPD) produces variable outcomes, and inappropriate procedure selection can lead to persistent speech impairment, repeat surgery, and prolonged therapy. In high volume cleft services, this represents a substantial burden for patients and multidisciplinary teaMs A predictive model combining perceptual speech assessment and video fluoroscopic measures, previously described by Bonanthaya et al., identifies patients in whom Furlow palatoplasty alone is unlikely to achieve competent velopharyngeal closure when the predicted postoperative closure ratio is below 0.8.

Aims and Objectives: To assess whether an algorithm-guided combined Furlow palatoplasty and pharyngeal flap improves objective velopharyngeal closure and perceptual speech outcomes in patients predicted to have poor outcomes with Furlow palatoplasty alone.

Methods: A retrospective audit was undertaken of 30 patients aged 6 to 22 years with VPD following primary palatoplasty, treated at a Smile Train Cleft Leadership Centre within a charity-run tertiary hospital in Bengaluru, India. All patients had a preoperative predicted closure ratio below 0.8 and underwent combined Furlow palatoplasty and pharyngeal flap as a single definitive procedure. Speech outcomes were assessed using the Henningsson et al. universal reporting parameters. Objective velopharyngeal closure was measured using closure ratio derived from lateral video fluoroscopy. Pre- and postoperative outcomes were compared using Wilcoxon signed rank testing.

Results and Conclusion: Postoperatively, 70% of patients achieved complete velopharyngeal closure, with a further 10% achieving efficient closure. Mean closure ratio improved by 0.51. Significant improvements were demonstrated in hypernasality, speech understandability, and speech acceptability ($P < 0.001$). In patients predicted to have poor outcomes with Furlow palatoplasty alone, an algorithm-guided combined approach delivers reliable improvements in both objective and clinically meaningful speech outcomes. Embedding predictive metrics within MDT decision making may reduce repeat surgery and prolonged therapy, supporting more efficient, patient-centred cleft care.

The association of speech development and language skills in 3-year-olds with cleft palate +/- lip

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Background: The Cleft Language and Auditory Skills (CLAS) study investigated the relationship between speech, language and auditory skills in children aged 5-8 years with non-syndromic cleft lip and palate (CLP). It found four distinct speech profiles – typical speech for age, cleft speech characteristics (CSC) only, developmental speech characteristics (DSC) only and a combined disorder of DSC+CSC. A significant association was observed between language and speech profile. Objective: To replicate these findings in children aged 3.

Method: Design: Prospective observational study
Participants: 56 children aged 3;0 to 3;11 with non-syndromic CLP born between 1/1/19 and 30/6/22.
Procedures: Children were seen for their routine 3-year check. Cleft SLTs administered standardised speech and language assessments.
Data collection: Data were entered onto a spreadsheet creating variables for the presence of CSC and DSC, and ordinal variables for expressive and receptive language skills (within expected range/mild delay/significant delay).
Data analysis: Data were analysed using descriptive statistics. Associations between speech profiles and language outcomes were explored using non-parametric tests.

Results: 29% had speech typical for their age; 48% of the group had DSCs, with the majority presenting with a combination of DSC+CSC. In terms of language, 77% had good receptive language and 48% had good expressive language. A significant association with speech outcomes and language skills was found for all measures, with those with DSC +/- CSC presenting with the poorest language skills.

Conclusions: Whilst the numbers in each subgroup were small, the findings support those of the CLAS study. Clinically this suggests that there is potential to improve outcomes in this population by providing intervention from 3-years that targets phonological processes impacting speech and language for those that present with CSC+DSC.

Comparing research publication with global orofacial cleft disease burden: whose voices are amplified?

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Introduction: The burden of disease of orofacial clefts (OFC) is greatest in Low and Middle income countries (LMICs), but these countries have historically been underrepresented in research literature.

Aims and objectives: This study aims to identify changes in inclusivity and representation of global OFC publications over 180 years and compare them with the global burden of disease.

Methodology: Articles published in Elsevier journals were examined using a Python script developed by the ICSR Elsevier Lab. All articles on OFC were selected. Articles in any language were included, provided they had an English abstract. Data extracted included journal of publication, geographical trends (including the most prolific countries and continents), country income status and first and senior author country of work and gender. Findings were compared with the latest global burden of disease data (Wang,2025)

Results/Conclusions: 39,176 articles met the inclusion criteria, published from 1842 to 2024. Publications numbers grew substantially after 1950, however only 22% of articles published since 2000 are open-access. The lead publishing countries in 2023 were the United States, China and the UK. While East Asia and the Pacific regions have shown significant growth in representation, Europe and North America still persistently lead publication outputs. More contributions from LMICs have been seen recently, despite high-income countries having historically dominated cleft research. Unfortunately, Southeast Asia, Africa and Latin America remain underrepresented, despite measurable improvements. Improved gender balance is evident, with a first author gender analysis showing increase from 20% in 1980s, to almost 50% in 2024. Despite evidence of persistent inequalities in cleft research, given by economical and gender disparities, some improvements in gender representation and global research output distributions are present. To foster a more inclusive research culture in the field, truly representative of global disease burden, a stronger international effort is encouraged.

Automated Classification of Maxillary Cleft Alveolus Sub-phenotypes Using 3D Neonatal Dental Models

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Background: Cleft lip and/or palate (CLP) is a common congenital craniofacial anomaly. Accurate classification of the cleft alveolus is essential for diagnosis, treatment planning, and large-scale epidemiological and genetic studies. However, routine assessment still relies on subjective visual inspection and palpation of the newborn's mouth or physical study models, which is time-consuming, difficult to standardize, and may cause discomfort. With the growing use of 3D neonatal dental models and intra-oral scanning, computational geometry provides an opportunity to automate and standardize cleft alveolus sub-phenotyping.

Aims: To develop a fully automated pipeline for classifying cleft alveolus from 3D neonatal dental surface models, focusing on the dento-alveolar component of clefting. The system classifies clefts by laterality (unilateral/bilateral) and completeness (complete/incomplete) in a reproducible manner.

Methods: We first normalize model pose using an oriented bounding box (OBB) to establish a local coordinate system. Alveolar peaks are detected automatically and used as seeds for a multi-stage region-growing algorithm to segment alveolar bone regions and determine laterality. Near-gap landmarks are then identified on the segmented regions, and Dijkstra's shortest-path algorithm is applied to model the cleft trajectory. Cleft completeness is determined by measuring shortest-path depth and width against predefined thresholds (4 mm and 5 mm, respectively). The method was evaluated on 20 clinician-annotated neonatal maxillary models.

Results/Conclusions: The proposed system correctly classified 18 out of 20 models (90% accuracy), with robust performance across varied cleft morphologies. On a standard desktop computer, most models were processed in a few seconds, enabling near real-time assessment. This automated approach supports standardized documentation of cleft

alveolus sub-phenotyping, reduces manual workload and has potential to improve clinical governance and research comparability in neonatal cleft epidemiology and care.

Bridging the Gap: a systematic review of learner perspectives on innovative technologies in cleft education

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Introduction: Technology-assisted education has revolutionised surgery, including orofacial cleft education(Dalgalı,2024). However, technology can also amplify educational disparities, as access is often limited to institutions or countries with sufficient resources(Han,2025).

Aims & Objectives: This paper systematically reviews the evidence supporting technology-enhanced education for cleft conditions, discussing how it complements traditional surgical education. It assesses geo-economic contexts in which these advancements have been trialled and identifies potentials for adaptation in diverse settings.

Methods: A keyword search in major databases including Google Scholar, PubMed, Scopus, and Medline was conducted. Articles were screened using Covidence. Only papers reporting learner outcomes were included for full-text screening. Both qualitative and quantitative analyses were applied, focusing on the country of study, income group, participants' training stages, intervention types, and impact on educational outcomes. A thematic analysis examined advantages like affordability, reproducibility, and technology fidelity.

Results/Conclusion: Out of 1,466 articles screened, 127 full-text studies were assessed, and 49 met inclusion criteria. In total, data from 2483 learners was summarised. 38 articles were published by high-income countries, 10 by low/middle-income countries(LMICs), while 2 involved cross-income group collaborations. Only one study represented a low-income country, Syria. Most studies came from the United States (20), followed by Canada (6), China and Germany (5 each).

Simulation was the most prevalent technological advancement with 32 examples, including 15 using 3D-printed models. E-learning (n=7) was the second most common, followed by AI, VR headsets and augmented reality. Confidence increase was discussed in 25 articles. Fidelity was addressed in 14 articles, with an overall rating of 70%.

Technology-enhanced cleft education has potential to improve educational outcomes, although learners' feedback should be more widely reported. Challenges include costs, reliance on the internet, and geographical inequalities were identified. Overall, a more equitable access across different geo-economic settings is encouraged, thus preventing widening inequalities.

Implementation Readiness and Barriers to Clinical Translation of AI in Cleft Care: A Systematic Review

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Introduction or Background: Artificial intelligence (AI) has demonstrated growing potential in cleft lip and palate care, particularly in diagnosis, treatment planning, outcome prediction, and surgical guidance. Despite increasing research activity, translation of AI technologies into routine clinical practice within multidisciplinary cleft services remains limited. Understanding implementation readiness and barriers is essential to bridge this gap.

Aims and Objectives: To systematically evaluate the implementation readiness of AI applications in cleft care, identify barriers to clinical adoption across technological, organisational and human domains, and propose strategies to facilitate successful integration into clinical practice.

Methods: A systematic review was conducted in accordance with PRISMA guidelines. Medline, Embase, PubMed, Emcare, Cochrane databases and grey literature were searched without date restriction. Seven hundred and forty seven studies published in English involving patients with isolated cleft lip, isolated cleft palate, or cleft lip and palate met the inclusion criteria for screening. Studies involving other craniofacial conditions were excluded. Two independent reviewers performed

data extraction and analysis. Implementation readiness was assessed using the Non-Adoption, Abandonment and challenges to Scale-up, Spread and Sustainability (NASSS) framework.

Results: Sixty-five studies published between 2008 to 2025 were included with a marked increase in publications in 2025 (48%). Barriers were identified across all seven NASSS domains: condition (49%), technology (80%), value proposition (31%), adopters (22%), organisation (3%), wider system (11%) and embedding and adapting over time (11%). While most studies (88%) proposed strategies to address these challenges, few reported real-world implementation or sustainability within clinical cleft services.

Conclusion: Significant barriers to clinical implementation of AI in cleft care persist, particularly at organisational and system levels. Addressing these challenges is critical for translating AI innovations into sustainable clinical tools, with potential benefits for patient outcomes, workforce efficiency and healthcare resource allocation, and equitable access to specialist cleft services.

Laser Therapy for Cleft Lip Scars: Evaluating Optimal Timing and Protocols Using Published Evidence

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Background: Systematic reviews have shown that laser therapy can improve post-surgical cleft lip scars. A recent review by Sun et al summarises this evidence. Despite efficacy, laser therapy is not routinely offered by many UK cleft services, and optimal timing, number of sessions, and session intervals remain unclear, limiting clinical guidance.

Aims: To explore how laser therapy can be applied most effectively by quantifying associations between treatment timing, session number, session interval and scar outcomes using data from published randomised controlled trials (RCTs).

Methods: RCTs included in previous systematic reviews were identified and key data extracted from published reports: Vancouver Scar Scale (VSS) outcomes, timing of initiation, session number, session interval, and laser modality. Meta-regression analyses examined associations between timing, session number and scar improvement.

Preliminary Results: Nine RCTs (429 participants) were included. Meta-regression suggested a negative association between delay in initiation and VSS improvement, with each month of delay associated with 0.85-point reduction. Initiating therapy within one month post-surgery was associated with a 1.7 to 3.3 point greater improvement than later initiation. Optimal session number was 4 to 6, with minimal additional benefit beyond this range. Session interval (2 vs 4 weeks) showed no significant effect.

Conclusions / Ongoing Work: These preliminary findings provide early evidence regarding timing and frequency of laser therapy for cleft lip scars. As many UK services do not routinely offer laser treatment, this work may inform future protocol development. Analyses are ongoing, and feedback from the CFSGBI community will help guide practical implementation strategies.

Beyond Multidisciplinary Care in Cleft Lip and/or Palate: Exploring Integrated Models

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Background: Children with cleft lip and/or palate (CLP) require long-term multi-disciplinary input. Although care is delivered through multidisciplinary cleft teams, aspects such as speech therapy, psychology support, and oral health advice are often provided separately. Integrated models of care may improve continuity across treatment stages, but it is unclear how well these approaches are supported by existing evidence.

Aim: To explore the evidence on integrated dental, speech, and motivational support for children with CLP and identify gaps relevant to cleft pathways and service development.

Methods: A scoping review was undertaken using JBI methodology and reported in line with PRISMA-ScR guidance, with the protocol registered on the Open Science Framework. Searches were completed across medical, dental, and psychological databases, clinical trial registries, and selected grey literature sources. Studies published from 2005 onwards were included without language restrictions. The review was carried out collaboratively by a dental trainee, orthodontic registrar, specialist librarian, NHS cleft consultant, and academic mentor. The consultant orthodontist met some authors of relevant studies at the international cleft congress in Japan.

Results: The searches identified 8,286 records from databases and trial registries, with around 500 additional records from grey literature. Very few studies described fully integrated CLP care pathways. Where integration was reported, this was usually limited to two areas of care with little evidence of models integrating dental, speech, and motivational support across treatment stages.

Conclusion: This review highlighted gaps in integrated cleft care. The findings helped inform a successful DENTSPASS grant application for a nurse-led integrated therapy model relevant to low- and middle-income countries. From a trainee perspective, the project showed how evidence mapping can extend beyond identifying gaps to informing service development and improving patient care, while supporting research skills and interest in further cleft research.

Reference
Ardouin K et al. Cleft Palate Craniofac J. 2025

Two types of nasal stents in cleft lip reconstruction: Experience from surgeon, nurses and parents

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Background: Achieving nasal balance at primary cleft lip reconstruction remains a substantial challenge. Nasal stents aim to mould the nasal cartilages and have been shown to improve appearance outcomes. Silicone stents were introduced into the cleft lip pathway at the start of a cleft surgeon's career in Wales, with a symmetrical commercial product used initially, followed by a transition to a customised in-house 3D-printed stent, which are asymmetric for unilateral cleft lips and symmetric for bilateral cleft lips.

Aims & Objectives: A consecutive series of nasal stents to assess experience of use.

Methods: Data was collected prospectively from a cleft surgical database for all children undergoing primary reconstruction of a unilateral or bilateral cleft lip. The type of nasal stent, length of time in situ and experience from surgeon, specialist cleft nurses and parents were recorded at the 6-week follow-up.

Results/Conclusions: 29 children underwent cleft lip reconstruction with the insertion of a silicone nasal stent. Commercial stents were used for the first 14 patients and customised in-house 3D-printed stents for the last 15 patients. Surgeon experience was positive for both stent types, with a beneficial impact of the stent observed to alar projection and dead space obliteration observed on table. Cleft nurses experienced an increased burden of care following the introduction of nasal stents and designed a nasal stent care pathway with advice from UK cleft units with prior experience. Parents reported nasal stent care to be the most challenging aspect in the post-operative period. The length of time the stents remained in situ reduced from an average of 2 weeks for the commercial stents to 1 week with the in-house stents.
This prospective and reflective audit of clinical practice will be combined with analysis of longer-term appearance and functional outcomes to influence decision-making regarding nasal stent use.

Collaborative design of a new multidisciplinary, multi-imaging modality one stop speech investigation clinic.

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Background information: The multi-modality speech investigation clinic has been pivotal in improving diagnosis and management of secondary cleft and non-cleft speech interventions. However, faced with broken infrastructure and suspension of all speech investigation clinics, an opportunity arose to develop a bespoke solution using technological advances to provide a service fit for the future.

Aims/objectives: To explore new technology opportunities to develop a one-stop clinic for assessment of velopharyngeal speech differences. This should provide screen-in-screen simultaneous images from videofluoroscopy, nasendoscopy, and high-fidelity speech recording. These should be viewable in real time and via playback in clinic and later, locally and regionally. Images should be editable to remove unnecessary segments and saved under patient details to ensure governance compliance.

Methods: Digital transformation teams were engaged as well as business analysis, systems mapping, and private sector providers. All associated cleft clinical specialties were involved. The clinical flow was systems-mapped and detailed process mapping achieved.

Results/conclusions: A new state of the art Speech Investigation (SPIN) Clinic has opened in the Bristol hub of the SW Cleft Service, utilising the Vidiview system by Eizo. One-stop speech assessment, incorporating videofluoroscopy and nasendoscopy imaging, is delivered by speech and surgical team members within a dedicated clinic space. Images are viewed simultaneously, with immediate playback available in the clinic. Images can be captured while the surgical team and parents observe and communicate from a separate viewing room, helping to reduce anxiety for younger or more reserved patients. Patients leave with an agreed management plan at the same appointment, reducing burden of care within our large regional area and facilitating earlier surgical listing, which contributes to improved clinical outcomes. Imaging is stored in a retrievable system, fully indexed to satisfy governance requirements. Imaging can be viewed later in clinic, office, or theatres via the platform.

Comparative Analysis of Presurgical Lip, Alveolus and Nose Approximation (PLANA) and Nasoalveolar Molding (NAM)

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Background: This study evaluates the Presurgical Lip, Alveolus, and Nose Approximation (PLANA) technique as a novel alternative to NasoAlveolar molding (NAM). The study hypothesizes that PLANA can achieve comparable Nasolabial outcomes to NAM while addressing its limitations, particularly by reducing the burden of care.

Methods: A retrospective review was conducted on 50 patients with non-syndromic unilateral or bilateral cleft lip and palate (CLP) treated with either NAM (n=28, including 2 treatment discontinuations) or PLANA (n=22). The overall physical burden of care was assessed in the full cohort. A subset of 25 patients with complete unilateral CLP (PLANA n=12; NAM n=13) was further analyzed to assess changes in nasolabial anthropometric ratios between cleft and non-cleft side using standardized 2D photographs taken pre-treatment (T1) and post-treatment (T2).

Results: The physical burden of care was significantly lower in the PLANA group, with 61.2 % fewer total office visits (5.2 vs. 13.4; $p<0.001$). The PLANA group also showed 72.19 % reduction in transient reversible side effects, such as oral, nasal, and cheek irritations (18.18% [n=4] vs. 65.38% [n=17]; $p<0.001$). PLANA achieved a significantly greater improvement in the columellar length ratio (0.53 vs. 0.37; $p = 0.026$), while NAM demonstrated a greater increase in the nostril height ratio (0.29 vs. 0.39; $p = 0.04$). No significant differences were observed in nostril width and alar base width ratios, or columellar deviation angle between the groups.

Conclusion: These findings suggest that PLANA significantly reduces the burden of care for patients with cleft lip and palate and may offer comparable nasolabial outcomes to NAM.

Remote clinician access to speech investigation clinics- using new technology to improve patient care.

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Background: the South West Cleft Service covers a large area of the UK from Gloucester to the Isles of Scilly. The service depends on regionally based specialist speech and language therapists to deliver therapy, but due to time and distances involved they are unable to attend speech investigation clinics at the Bristol hub with their patients.

Aims/ objectives: to fully utilise the potential in emerging technological developments to enable regionally based speech therapists to attend cleft hub-based speech investigation clinics.

Methods: early engagement was made with development of a new bespoke multi-modality speech investigation clinic. Discussions between digital transformation, business analysis and systems mapping, and private sector providers were held. Moon shot explanations of possible changes in working practices in cleft speech care provision were given.

Results/ conclusions: early experience of the newly functioning clinic utilising virtual engagement with spoke speech therapists has been groundbreaking. The new digital platform has been set up in a way to allow remote real time viewing of the clinic, the child in the clinic, videofluoroscopy and, where undertaken, simultaneous nasendoscopy. This has greatly improved the therapists' knowledge of the functional anatomy for their own patients to facilitate targeted therapy. The spoke SLTs know their patients well and can interact with them during the clinical assessment and offer advice and information to the hub team in real time. This has already proven to be of significant benefit to apprehensive patients. In addition there has been the educational clinical benefit to the regionally based clinicians.

Dental anomalies in cleft lip/palate children attending a specialised cleft centre in the UK

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Introduction: Cleft lip and/or palate (CLP) are common congenital craniofacial conditions associated with a high burden of dental anomalies requiring specialist multidisciplinary management.

Aim: To assess the prevalence of dental anomalies in children aged 10 to 16 years with CLP and to identify the most common anomalies and their link to cleft type.

Methods: A retrospective service evaluation was conducted using anonymised clinical data. The study was conducted at the Evelina London Cleft Service, a specialised cleft centre in the UK. The study included a convenient sample of 123 children aged 10 to 16 years with a confirmed CLP diagnosis who were attending the Evelina London Cleft Service. The primary outcome measures were the prevalence of dental anomalies, including hypodontia, supernumerary teeth, ectopic eruption, impaction, and enamel defects. Secondary measures included DMFT scores, malocclusion status, and the presence of underlying medical conditions.

Results: The cohort of 123 children was predominantly male (59.4%) with a mean age of 12.4 years. Cleft palate was the most frequent diagnosis (25.2%), followed by unilateral CLP (22.0%) and bilateral CLP (17.1%). Hypodontia was the most prevalent dental anomaly, affecting (39.0%) of children, with the maxillary left lateral incisor most affected. Other significant findings included supernumerary teeth (16.3%) and enamel hypomineralisation (15.5%). The mean DMFT score was low at (0.69), reflecting a low caries rate. Skeletal and incisor Class III relationships were most common in patients with unilateral and bilateral CLP, while Class I patterns were more frequent in those with cleft palate.

Conclusion: Dental anomalies, particularly hypodontia, are highly prevalent in children with CLP, with patterns varying by cleft type; these findings are in agreement with published research and emphasise the importance of early detection and the critical role of multidisciplinary cleft teams in delivering collaborative, comprehensive care.

MRSA Screening in Cleft Surgery Patients: A Retrospective Audit

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Background: Methicillin-resistant staphylococcus aureus (MRSA) poses a significant risk for surgical site infections, potentially compromising outcomes following cleft surgery. Our local guidelines differ from most regional cleft centres in mandating pre-operative MRSA screening. However, adherence to these protocols can vary, impacting patient safety and experience.

Aims & Objectives

- Assess compliance with local trust guidelines for pre-operative MRSA screening in patients undergoing cleft surgery.
- Assess the financial impact of pre-operative screening on carers/parents.

Methods: A retrospective audit of all patients undergoing cleft surgery over a six-month period (01/05/2025-31/10/2025) at Birmingham Children's Hospital was conducted. Patients undergoing alveolar bone graft procedures were excluded. Demographic, procedural and MRSA screening data were extracted from electronic medical records. The standard for compliance was set at 100% in accordance with local trust guidelines. Mileage and travel expenses for pre-operative MRSA screening were calculated using the AA mileage calculator.

Results: Over the study period, 85 cases were identified. Patients had a median age of 0.99 years (range 0.29-17.15 years). Procedures included cleft lip repair (33%), cleft palate repair (34%), pharyngoplasty (18%) and other cases such as palatal lengthening, palatal fistula repair and rhinoplasty (15%). Most patients (99%) had an MRSA swab taken pre-operatively, with two-thirds of these appropriately taken in the outpatient setting within four weeks prior to admission. All MRSA swab results

were negative. Patients travelled a median of 44.7 miles (range 5.4-357.6 miles), with an average travel expense of £10.55 (range £4.46-£60.42).

Conclusions: Despite our department demonstrating good adherence to the MRSA screening protocol, the process imposes a considerable financial and logistical burden on patients and their families. Additionally, given the lack of positive swabs, there were no direct adverse effects on the surgical pathway. Further work will re-audit the impact of removing pre-admission MRSA screening on patient pathways and the individual experience.

A Retrospective Review of Speech Outcomes Following Submucous Cleft Palate (SMCP) Repair

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Background: Submucous cleft palate (SMCP) is defined as a cleft in the palatal muscles beneath intact oral mucosa. They are often diagnosed later in life, presenting with velopharyngeal dysfunction (VPD) and hyper-nasal speech.
Primary surgery aims to re-align the palatal muscles to improve palate function and speech, typically via Intravelar-Veloplasty (IVVP) or Furlow palatoplasty. Speech outcomes are measured both pre- and post-operatively using the Great Ormond Street Speech Assessment (GOS.SP.ASS).
Approximately 20 – 30% of children born with cleft palate will require secondary speech surgery, however there is limited SMCP-specific evidence.

Aim: Identify the proportion of SMCP patients who require further speech surgery following primary repair.

Method: A retrospective audit of patients who underwent SMCP repair in our regional cleft service from 2015 – 2025.

Results: Forty-six patients with primary SMCP repair (Furlow >50%; remainder IVVP) were identified. Ten patients had a syndromic diagnosis, most commonly 22q11 Deletion Syndrome, which is known to increase risk of VPD.
All patients were reviewed six months post-operatively with GOS.SP.ASS scoring. Patients were subsequently discharged to routine review or referred for further assessment with videofluoroscopy, to consider secondary speech surgery.
Overall, 28% required secondary speech surgery and 11% had persistent speech difficulties pending assessment with videofluoroscopy.
Furlow palatoplasty was the most common secondary speech surgery, followed by pharyngoplasty; buccal flaps were used in a single case to lengthen the palate.

Conclusions: In this single-centre cohort of 46 children born with SMCP, 28% required secondary speech surgery. This lies towards the upper end of reported rates after primary cleft palate repair, but interpretation is limited by the small sample size. There was no statistically significant difference between IVVP and Furlow in subsequent need for secondary speech surgery (IVVP 24% vs Furlow 31%; p=0.74).
Larger multicentre studies are needed to validate and refine these preliminary results.

Aesthetic Rehabilitation of a Cleft Lip and Palate Patient with Fixed Prosthodontics

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Background: Adult patients with cleft lip and palate (CLP) frequently present with residual aesthetic and occlusal challenges despite previous multidisciplinary care. Fixed prosthodontics can provide a predictable and conservative approach to improving aesthetics while accommodating compromised anatomy and reduced tooth support.

Aims & Objectives: To demonstrate the role of fixed prosthodontic rehabilitation in improving anterior aesthetics and patient satisfaction in a patient with bilateral CLP.

Methods: A 30-year-old female with a history of bilateral CLP was referred by a specialist orthodontist due to dissatisfaction with her smile, particularly in the anterior maxilla. Clinical examination revealed mild facial asymmetry, a low smile line with limited upper lip mobility, a Class III incisal relationship, UR2 in crossbite, and a left lateral open bite. The dentition was moderately restored, with bulky composite restorations on UR1 and UL1 and two resin-bonded bridges replacing the large

mesiodistal space of the missing UL2 using two small pontics. External root resorption affected UR2, UR1, and UL1, with Grade III mobility of UR2. Following digital smile analysis and wax-ups, UR2 was extracted and the existing left-sided bridgework dismantled. An immediate interim partial denture was provided to maintain aesthetics. Anterior composites were removed, and UR1 and UL1 were prepared for ceramic veneers. Resin-bonded bridges were planned with a palatal wing on UR3 to replace UR2 and a metal–ceramic buccal wing on UL3 to replace UL2. Final restorations were cemented, and an Essix retainer was provided.

Conclusions: This fixed prosthodontic approach improved smile aesthetics while avoiding implant placement, removable prostheses, and irreversible preparation of teeth. The patient reported improved confidence and satisfaction with the aesthetic outcome. This case highlights the value of carefully planned, digitally supported fixed prosthodontics in managing complex aesthetic concerns in adult cleft patients as part of comprehensive multidisciplinary care.

A subsystems approach to establishing norms for speech, voice, and resonance: The VariCS Project

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Introduction: While norms are fairly well established for phonological development, there is a relative lack of normative data for articulation, respiration, phonation, and resonance, especially in primary school-aged children. This makes it challenging to compare children with cleft and craniofacial conditions to their peers. The Variability in Child Speech (VariCS) project comprises audio recordings from almost 300 children in Scotland aged five to twelve years. The corpus systematically charts cross-sectional and longitudinal variability in acoustic measures of child speech for respiration, phonation, resonance, and articulation.

Aims and Objectives: This research aims to make longitudinal normative acoustic data accessible to SLTs to use in clinical practice via an open access web resource.

Methods: Data was collected via an iPad app. Children were aged 5-12 at the outset of data collection and data were collected four times at six-month intervals. The data comprise the Diagnostic Evaluation of Articulation and Phonology Screen (DEAP); a story retell; picture description; sentence repetition; single word picture naming of 22 single syllable words to elicit corner vowels and selected consonants; and maximum performance tasks.

Analysis comprises quantitative acoustic measures for all subsystems plus perceptual phonetic analysis of the DEAP screen including percentage consonants correct.

Results/Conclusions: Interim analysis shows substantial variation and wide ranges in the subsystems analysed. Analysis of the DEAP showed a mean percentage consonants correct of 96.97% (SD= 8.23) with some persisting phonological patterns and phonetic distortions in children over five years. Taken together these data serve as realistic comparative data for children with all types of speech and voice disorders including cleft and craniofacial conditions. An interactive website with a look-up facility is under construction to allow practitioners to easily compare children's values to normative data. This will allow objective assessment of speech, voice and resonance for children with cleft and craniofacial conditions.

Inclusivity in Cleft Care: Are we meeting the needs of our paediatric neurodivergent patients?

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Background: Research suggests individuals with orofacial clefts (OFC) may be at increased risk of autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD) (Cook et al., 2024). Individuals with OFC and co-occurring neurodivergence and/or SEN can find many aspects of cleft clinic appointments overwhelming: loud, busy waiting rooms, attending multiple appointments in a single day, and meeting unfamiliar adults. This overwhelm can result in dysregulation; patients being unable to engage during their appointment or carry out the tasks required of them. Concerningly, this may prevent patients receiving accurate assessment and subsequent treatment of their cleft-related needs.

Aims/Objectives:

- To examine whether neurodivergent patients and their families attending cleft appointments feel we are adequately meeting their needs
- Use this feedback to make/work towards service improvements where possible

Method: Data was collected via questionnaires distributed by the Manchester/Alder Hey cleft services MDT during clinic appointments from September 2025 to January 2026. Questionnaires were distributed to patients with documented neurodivergence, or those who reported challenges attending appointments/were awaiting neurodivergent assessment. The questionnaires were predominantly completed by the parent/carer, with input from the child in the appropriate sections.

Results: Interim results from 20 questionnaires thus far suggest patients are mostly satisfied with the care received from the MDT in relation to consideration of their neurodivergence. Common themes are emerging however which include a lack of awareness of available resources and the impact waiting for appointments can have on mood/behaviour. Full analysis of the results will be discussed when all responses are collated.

Reference: Cook B, Van Bockstaele S, Crow SB, Sainsbury D, Butterworth S, Filson S. Neurodevelopmental disorders in children with cleft lip and palate: a systematic review. Eur Child Adolesc Psychiatry. 2025 Jun;34(6):1731-1738.

Cleft and Craniofacial Clinicians' Experiences of International Conference Attendance: A Qualitative Service Evaluation

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Background: International conferences are an important component of clinicians' continuing professional development, facilitating knowledge exchange, interdisciplinary collaboration, and professional identity. They also provide valuable opportunities to connect with experts and peers from diverse regions, helping clinicians build lasting professional relationships and identify potential mentors or collaborators (Acuña Mora & Borregaard (2024).

Evidence consistently shows that face to face conferences support richer informal interaction and networking (Zajdela et al., 2025), while virtual formats improve accessibility, reduce costs and travel burden (Dumbell & Haddow, 2024). Qualitative studies highlight differing engagement experiences: virtual conferences provide flexibility but may reduce opportunities for interpersonal connection (Gottlieb et al., 2022). As hybrid formats become more common, there is a need to understand how clinicians within cleft and craniofacial services experience and value these evolving modes of conference participation.

Aims & Objectives: To explore clinicians' perceptions and experiences of international conference attendance over the past five years, examining perceived value, benefits, challenges, and preferences across face to face, virtual, and hybrid formats.

Methods: A qualitative service evaluation was conducted using an online questionnaire with open ended questions distributed to clinicians working in cleft and craniofacial care. Data collection is now complete. Free text responses are currently undergoing reflexive thematic analysis following Braun and Clarke's (2022) inductive approach. The analysis is in its final stages, supported by iterative coding, reflexive engagement, and documentation consistent with recognised criteria for qualitative rigour (Nowell et al., 2017).

Results/Conclusions: Early analysis indicates clear and meaningful patterns relating to clinicians' experiences of different conference formats. The evaluation is expected to provide insight into the role of conference participation in supporting interdisciplinary learning, accessibility, professional identity, and collaboration within cleft and craniofacial care. These insights will help inform future conference planning, particularly in balancing accessibility, cost effectiveness, and opportunities for meaningful engagement across delivery formats.

The online presence of cleft units in the UK and Ireland

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Background: Online content is a vital source of information to patients and their families. The #cleftlip tag alone has 177,000 posts on Instagram and the majority of patients' families use social media to access cleft-related content, particularly for education on diagnosis/management. The CleftTok study found that TikTok content produced by clinicians was more reliable and accurate than that produced by non-clinicians. However, it also found that clinicians are underrepresented.

Aims: To establish the online presence of cleft units in the UK (UK) and Ireland.

Methods: Instagram, TikTok, X (formerly Twitter), and Facebook were searched for official accounts run by Cleft Units in the UK and Ireland. Data collected included whether the accounts were active and number/theme of posts in 2025. Cleft unit websites were appraised for the following content: staff profiles, how to make a referral, patient information leaflets, contact details, patient journeys, and the care timeline.

Results: One unit had an active Instagram account. They made 22 posts in 2025. The majority of these were about conference attendance and research recruitment (both 23%). Two units had official Facebook groups. Common themes were events (30%) and campaigns (21%). None of the cleft units had TikTok or X accounts; all had websites. All websites provided team contact details, 87% provided patient information leaflets, 73% explained how to make a referral, 60% of websites listed the team, 40% presented a care timeline and 27% provided patient journeys.

Conclusions: There is a lot of information available on social media about cleft lip and palate, but it is mostly not produced by cleft units in the UK and Ireland. Unit websites are a good source of information, but are inconsistent across units. Units should consider establishing a social media presence, and work with patients and their families to ensure their websites are adequate.

Pre-operative NPA Use Predicts Post-operative NPA Use Following Primary Palatoplasty in PRS: A Regional Review

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Background: Airway compromise following palatoplasty in infants with Pierre Robin sequence (PRS) is a well-recognised peri-operative concern. Although several risk factors have been described, reliable and pragmatic predictors of post-operative nasopharyngeal airway (NPA) requirement remain limited, with important implications for peri-operative planning and parent counselling.

Methods: A retrospective regional review was performed of infants with PRS undergoing cleft palate repair within a regional cleft service. Baseline demographic, clinical and airway variables were collected, including PRS severity grade, syndromic status/comorbidities, and pre-operative NPA use. The primary outcome was post-operative NPA use. Secondary outcomes included duration of post-operative NPA and length of stay (LOS). Associations were assessed using Fisher's exact test and effect sizes estimated.

Results: Thirty infants underwent palatoplasty during the study period; all had definitive pre- and post-operative NPA status. Post-operative NPA was used in 11/30 (37%). Post-operative NPA was required in 7 of 11 infants with a history of pre-operative NPA (64%), compared with 4 of 19 infants without prior NPA (21%) (risk ratio 3.0; odds ratio 6.6; Fisher's exact p=0.046). Where used, post-operative NPA duration was short (median 1 day; no cases >1 day recorded). LOS was typically 2 days in infants requiring post-operative NPA versus 1 day in those without. No infants developed new prolonged airway difficulties after the initial post-operative period.

Conclusions: In this regional review, prior requirement for NPA pre-operatively was the most practical predictor of post-palatoplasty NPA use. Importantly, post-operative NPA use was usually brief, associated with minimal additional inpatient stay and no patients developed long-term airway probleMs These findings support the use of NPA for the management of PRS in the post-operative period and help with pre-operative parental counselling.

Same day discharge of patients undergoing alveolar bone grafting leads to significant savings

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Introduction: Alveolar bone grafting has historically been regarded as having the potential for significant post-operative pain. Over the last decade it had been observed at our institution that children were tolerating alveolar bone grafting (ABG) far better than previously. Auditing existing analgesia regimes found no difference between oral and parenteral administration.
Same day discharge has significant benefits for both patient experience and cost of the patient episode. Following an initial trial of same day discharge, receiving very positive parent and patient feedback, we moved to routinely performing ABG as a day-case procedure in 2022.

Aims and Objectives: This project aimed to determine current average length of stay and same day discharge rates for patients undergoing ABG and calculate the relative cost saving for the Trust.

Methods: 275 patient records were reviewed encompassing all patients who underwent ABG between January 2018 and May 2025. The average cost of a 24hr inpatient bed stay was calculated using financial data from the first 5 months of 2025.

Results and conclusions: After introducing the change in policy to performing ABG as a day-case procedure in 2022 there is a downward trend in length of stay from a stable baseline. The proportion of patients discharged the same day has gone from <10% prior to 2022 to nearly 90% in the first half of 2025. With a 24hr paediatric inpatient bed stay costing an average of £694, this equates to a saving of £13,880 for the first half of 2025. This trend was independent of named lead surgeon or mode of anaesthesia.
With catchment areas for the majority of UK cleft centres being large, achieving 100% same day discharge is unrealistic, however we show that getting close to this is both achievable and financially attractive.

Does high intensity group speech therapy facilitate improvements in speech outcomes?

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Background: By age 5, 38.8% of children born with cleft lip and palate have not achieved typical speech (Decon et al, 2018). Those who receive speech therapy have less speech errors (Sell et al, 2017). Frequent speech therapy can improve progress over a shorter period (Alighieri et al., 2021), whilst group therapy provides a more natural communication environment in which patients can learn from others (Farquhar and Hammond, 2022).

Aim: To improve speech outcomes for children experiencing cleft speech characteristics through high intensity group speech therapy (IGST).

Method:

- 3x 1-hour sessions of group articulation therapy were delivered each week for 2-weeks.
- Therapy activities were demonstrated and scaffolded to enable parents to repeat activities independently.
- Speech was analysed on a numeric scale following the articulation steps (Van Riper, 1939), where 1 is consonant in isolation and 13 is consonant generalised (Pamplona, 2014). •Speech was measured immediately before, immediately after and a month after attending IGST.

Results:

- 17 children aged 3 – 11 attended with 11 males and 6 females of which 7 were born with Cleft Palate, 3 with UCLP, 3 with BCLP and 4 with noncleft VPD.
- 82% of children showed improvements in speech immediately after IGTS.
- A month after IGST (during which no speech therapy was provided), 29% of children continued to demonstrate improvements in their speech sounds whilst 65% of children maintained the sound worked on.
- The children aged 7-11 years made the best progress with 4 of these children increasing 10 points during IGST.
- The children starting at the lower end of the point scale to learn a sound in isolation made the best progress.

Conclusion: This proved to be a successful pilot. The majority of children made improvements in speech outcomes while attending IGST.

Parents were provided with strategies to independently support their child following IGST.

Functional Rehabilitation of a Cleft Lip and Palate Patient With Removable Prosthodontics

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Background: Patients with cleft palate frequently present with complex restorative challenges, including compromised occlusion, altered vertical dimension, and difficulty achieving stable removable prostheses. Long-term success relies on careful occlusal management, appropriate prosthesis design, and patient-centred decision-making. This case describes the functional rehabilitation of a cleft palate patient using a removable overlay prosthesis and highlights clinical considerations when digital and conventional fabrication workflows are employed.

Aims & Objectives: The aim of this case was to restore function, comfort, and occlusal stability in a cleft palate patient with a pronounced bilateral posterior open bite who was dissatisfied with an existing removable overlay prosthesis, while preserving the established occlusal vertical dimension and minimising biological and technical risk.

Methods: A 51-year-old female with a bilateral cleft hard palate and Class III skeletal relationship was referred with a failing lower overlay cobalt-chromium partial denture. The prosthesis increased occlusal vertical dimension and provided a removable occlusion but was associated with acrylic chipping, reduced function, and dissatisfaction. Examination revealed bilateral posterior open bites, fair oral hygiene, a heavily restored but generally well-maintained dentition, BPE scores of 2–3, and generalised gingivitis. Treatment options included like-for-like replacement or full occlusal rehabilitation using fixed restorations. The patient chose a conservative approach. Digital intra-oral scans and a copy scan of the existing denture were used to fabricate a like-for-like metal framework without an acrylic occlusal overlay. Due to distortion related to the digital sintering process and subsequent instability, treatment was converted to a conventional handcrafted cobalt-chromium framework. Composite was placed on the lower left second premolar to improve clasp retention.

Results / Conclusions: The definitive prosthesis demonstrated excellent fit, stable intercuspal contacts, and even bilateral occlusion. At four-week review, the patient reported satisfactory function, improved comfort, stable retention, healthy soft tissues, and enhanced speech and mastication.

SATB2-associated syndrome and Cleft Palate: Management of spontaneous dental abscesses in a two-year-old child

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Background: SATB2-associated syndrome (SAS) is a rare genetic condition caused by variation in the SATB2 gene affecting brain, bone and tooth development. Common features are developmental delay, delayed/absent speech, and craniofacial abnormalities, including, cleft/high-arched palate (approximately 45% of cases). Dentally: taurodontism, wide apices, hypodontia, and spontaneous periapical abscesses are often present.

Aims & Objectives:

- To discuss the presentation, diagnosis and management of a patient with spontaneous periapical abscesses.
- To raise awareness of SAS, particularly to Cleft MDTs, highlighting their instrumental role in diagnosis.

Methods: Records were reviewed.

Results/conclusions: A two-year-old patient, already known to their Cleft MDT, presented to the Paediatric Dental Department on referral from the Community Dental Service, due to a spontaneous periapical abscess in the absence of caries or trauma. The patient was non-verbal with neurodevelopmental delays. Initial findings included an absent primary lower lateral incisor (LLB), and a periapical abscess associated with a primary upper central incisor (URA). Limited cooperation meant initial management utilised antibiotics. While awaiting a treatment under General Anaesthesia (GA), the patient re-

presented with further abscesses on multiple teeth. Under GA, primary teeth, including all A's, B's and D's were extracted, and E's and C's (which showed no pathology) were protected with Hall Crowns and composite coverings.

Initially suspected as hypophosphataemia or hypophosphatasia, extracted teeth were sent to histopathology. Investigation revealed these diagnoses were not the cause. Genetic testing was arranged, at age four, by the Cleft MDT, giving a diagnosis of SAS. Subsequently, all primary C's developed periapical abscesses and were extracted under GA. No further dental invention has been required since.

To conclude, presence of spontaneous periapical abscesses in patients with a cleft palate alongside neurodevelopmental delays should prompt investigation into genetic conditions such as SAS. Early MDT involvement, including accessing genetic testing was advantageous, and could be for others.

The developmental trajectory of communication outcomes in Robin Sequence (RS) and isolated cleft palate (iCP)

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Background: Robin Sequence (RS) is a congenital disorder with characteristics of micrognathia, glossoptosis and airway difficulties +/- cleft palate. Much research has highlighted poorer speech outcomes in this group compared to peers with isolated cleft palate (iCP) (Filip et al., 2015; Hardwicke et al., 2016). However, few studies have investigated language skills and social communication in this population.

Current literature around communication outcomes in children with RS are limited by small sample sizes and often group syndromic and non-syndromic RS cases as single cohorts. No studies have looked at longitudinal communication outcomes across ages of crucial development, making this the first study to compare social communication, expressive and receptive language skills from 18 months to 8 years between children with non-syndromic RS and children with iCP.

Aims: This study aims to explore the trajectory of communication development in children with non-syndromic RS and iCP across four developmental stages.

Methodology: This study uses secondary data analysis of parental-reported questionnaires from the UK Cleft Collective collected at 18 months, 3 years, 5 years and 8 years. Descriptive and inferential statistics will be performed to examine cross-sectional differences across domains at each age group. Where data is available, within-subject longitudinal analyses will be conducted.

Results: Data analysis is ongoing and results will be presented outlining parent reported outcomes in social communication and expressive and receptive language skills at all age points. These will be presented alongside the same data from the iCP group to provide clear comparisons.
Impact
By comparing communication outcomes in both cohorts, this study will identify differences across time and patterns of development to highlight potential gaps. This will inform early intervention and resource allocation.

Talking Takes Time and I Did It: A pilot resource for therapy transitions

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Background: Speech therapy for children with cleft conditions is often a long-term intervention. Therapy sessions are engaging and play-based involving consistent 1:1 interaction with the therapist. This supports effective speech outcomes; however, it can also make the transition out of therapy challenging, with recent observations highlighting younger children becoming upset when therapy comes to an end.

Difficulties surrounding transition are also reflected in older populations. Davies, Owen & Burton (2026) explored experiences of young adults in cleft services and highlighted that transitions between stages of care were often described as emotionally challenging, particularly due to the close therapeutic relationships formed- suggesting the emotional impact of ending cleft care may be underestimated.

While the primary aim of speech therapy is achievement of speech goals, these findings highlight the importance of considering how therapy endings are managed. Supporting children to understand the completion of therapy may help them leave the service feeling supported rather than abandoned.

Aims:

- To support children in preparation for the end of speech therapy
- To provide children with a resource that allows them to reflect on and celebrate their therapy achievements
- To evaluate the effectiveness of the resource in supporting transition at discharge

Method: Data was collected between 2025-2026 from five patients aged 5–9 years (2 female, 3 male)- these children had received regular speech therapy for between two to seven years. An interactive booklet was introduced at the end of therapy for children to take home and complete with caregivers, reflecting on skills gained during therapy. Caregivers completed a feedback questionnaire following the end of therapy, self-assessing whether the resource supported their child's transition from therapy.

Results: Preliminary caregiver feedback has been positive, with parents expressing enthusiasm for the resource and its use at the end of therapy.

Mapping the landscape of congenital anomaly registries worldwide: The role of Health and Economic factors

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Background: Babies in the UK receive care from specialist cleft nurses within a few hours of birth. This requires newborn screening for congenital anomalies (CA), prompt referral and robust registries. Globally 1 in 4 children under age 5 are not officially registered (UNICEF, 2019). This global 'scandal of invisibility'(Setel, 2007) must be addressed to ensure that any baby born with a cleft is referred early enough to prevent morbidity and mortality.

Objectives: To evaluate broader systemic factors contributing to the lack of CA recording globally. By studying:

1. prevalence of national and/or regional congenital anomaly registers (CARs) globally
2. differences in key economic and health indicators in countries with and without CARs.

Methods: A wide range of databases and literature were searched to determine the existence of CARs in all UNICEF listed countries. Countries were classified according to CAR status into those that had 1)a national CAR with/without regional CAR, 2)only regional CAR(s) 3)no CAR data available. These data were correlated with country income group, and health and economic indicators from UNICEF and the World Bank.

Results/Conclusions: 30/196 countries had a national CAR, 19/196 had a regional CAR and 147/196 had no CAR. Analysis by country income group showed that national CARs existed for 35% of HICs, 13% of UMICs and 0% of LMICs and LICs.

Countries lacking a national CARs have lower GDPs, increased infant mortality rates (IMR) and lower birth registration rates (BRR).

While the importance of CARs to improve global health is widely recognised, most LMICs and LICs still do not report having a national CAR. Our study suggests that countries without CARs face greater economic and health systems challenges with lower GDP, lower BRR and higher IMR Collaborations to improve global cleft care also need to consider these broader health/economic challenges to achieve sustainable progress.

Co-Design and Development of a Cleft-Specific Digital Speech Therapy Platform

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Background/Introduction: Children with a cleft palate often require prolonged speech and language therapy, with effective parent-supported home practice recognised as central to improving outcomes. Within NHS cleft services, traditional paper-based home speech practice presents challenges, including variable adherence, limited monitoring, and reduced caregiver confidence. Despite growing interest in digital health solutions, there are currently no widely available platforms for home practice to support the treatment of cleft-related speech errors.

Aims & Objectives:

1. To describe the clinical, evidence-based, and user-centred work informing the design and development of SpeechPath, a cleft-specific digital speech therapy platform.
2. To outline its progression to a Minimal Viable Product (MVP) ahead of feasibility testing.

Methods: A mixed-methods pre-implementation approach was undertaken within a tertiary NHS cleft service. This included: (1) a review of the literature relating to parent-implemented speech therapy and digital interventions; (2) structured workshops with specialist cleft Speech and Language Therapists (SLTs) to identify unmet clinical needs and desired platform features; (3) consultation with young people with lived experience of speech therapy through a hospital youth forum; and (4) market analysis of existing speech therapy applications to assess suitability for cleft speech. Findings informed the co-design of SpeechPath, with development supported through Alder Hey Strategic Funding (£13,800).

Results/Conclusions: Pre-development work identified key requirements for a cleft-specific digital platform, including cleft-appropriate sound selection, parent guidance, gamification to support motivation, clinician-led prescription, and progress monitoring. SpeechPath was developed as an MVP incorporating these features and embedded within routine clinical pathways. This work demonstrates a structured, clinically driven approach to digital innovation in cleft care, provides a foundation for subsequent feasibility evaluation, and offers a model for future digital SLT tools.

1 Melvin et al., 2020
2 Hajesmaeel-Gohari et al.,2023

Quality of Life in Sri-Lankan Adolescents with Cleft Lip and Palate: Generic versus Condition-Specific Instruments

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Introduction: Cleft lip and palate (CLP) and its long-term treatment can substantially affect adolescents' daily functioning and wellbeing beyond clinical outcomes. While generic health-related quality of life instruments such as the Paediatric Quality of Life Inventory (PedsQL) provide an overview of overall health status, they may not adequately capture the condition-specific challenges related to oral function, facial appearance, speech, and social interactions experienced by individuals with CLP. Oral health-related quality of life measures, particularly the Child Oral Health Impact Profile (COHIP), are considered more sensitive and responsive for this population, as they specifically address the functional, emotional, and social impacts associated with craniofacial anomalies.

Aims: To translate and validate COHIP into Sinhala and investigate quality of life (QoL) in adolescents (age 12-15 years) with repaired CLP using a generic and condition specific assessments.

Methods: The COHIP English assessment was translated into Sinhala following the forward - backward - forward method by a bilingual expert panel. Final COHIP-Sinhala (COHIP-S) translation was checked for linguistic and conceptual equivalence to the original before piloting. There were 348 adolescents in total (aged 12-15): 340 typically developing (TD) and 44 with repaired CLP completed the COHIP-S. The PedsQL- Sinhala generic QoL questionnaire was completed by 318 TD and 43 CLP adolescents.

Results/Conclusion: The translation and cultural adaptation process produced the final Sinhala version of the COHIP (COHIP-S). The COHIP-S demonstrated high internal consistency, with Cronbach's alpha values of 0.75 for TD adolescents and 0.76 for adolescents with CLP. Adolescents with CLP reported significantly lower QoL compared with their TD peers. Both the COHIP-S and the PedsQL-Sinhala instruments successfully discriminated QoL differences between TD adolescents and

those with CLP; however, the condition-specific COHIP-S demonstrated greater sensitivity in capturing the oral health-related QoL impacts associated with CLP.

Reported Patient and Parent Experience Post Alveolar Bone Graft Surgery within a Regional Cleft Unit

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Background: Alveolar bone grafting (ABG) has traditionally resulted in an overnight stay in hospital. Research highlights day-case ABG is feasible, safe, improves resource utilisation and patient satisfaction, Shah et al, (2025). A satisfaction survey conducted within the Cleft Unit (2024) explored experiences following ABG. Findings reported mixed views regarding discharge timing, some parents supporting an earlier discharge whilst others requested more support for pain management. Day-case is not suitable for all children. Factors such as cleft type, co-morbidities, family confidence and distance from hospital may preclude day-case surgery. A move towards day-case ABG may be offered on an individualised basis rather than as a universal pathway.

Methods: A retrospective, record review of all children receiving an ABG between October 2024-December 2025 was conducted. All children were included in the data collection, regardless of cleft type, co-morbidities or long travel which may have influenced day-case ABG. A retrospective service evaluation was undertaken via a structured telephone questionnaire with the children's families examining pain management, use of take-home morphine, satisfaction with length of stay and suggestions for improvement.

Results: 38 children received ABG surgery during the timeframe. 21 patients (55%) were managed as day-case, while 17 (45%) required admission (14 for one night, 2 for two nights and 1 for three nights). During this period, the surgeon and wider medical team decided on child's length of stay in hospital. Reasons for delayed discharge and feedback on patient/ family experiences will be reported in more detail.

Conclusion: Day-case ABG is feasible and well-accepted for carefully selected children. Whilst not suitable for everyone, evidence supports offering same-day discharge on an individualised basis, considering cleft type, co-morbidities, and distance from emergency services. Enhanced pre-operative discussion and standardised discharge guidance are essential to optimise family experience and support safe expansion of day-case ABG pathways.

Facial Implant Infection Rates in Cleft Patients: A Ten-Year Retrospective Analysis

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Background or Introduction: Midfacial hypoplasia and asymmetry are characteristic features of cleft lip and palate patients. Alloplastic facial implants, particularly porous polyethylene (Medpor), offer effective midface contouring. However, infection remains a recognised complication that may necessitate removal. Site-specific infection rates in cleft populations remain poorly characterised in the literature.

Aims & Objectives: To determine the infection-related removal rate of Medpor paranasal and malar facial implants in cleft patients, and to evaluate whether infection risk differs by anatomical location.

Methods: A retrospective analysis was conducted of all Medpor paranasal and malar implants placed by a single surgeon at the Evelina Cleft Service between 2012 and 2023. Patient demographics, implant characteristics, and removal data were collected from electronic theatre records. Primary outcome was the rate of implant removal due to infection. Infections were classified as occult infection (chronic symptoms without acute inflammatory signs) or low-grade infection (persistent discomfort attributed to subclinical bacterial colonisation).

Results: Fifty-five patients (33 female, 22 male) received 129 Medpor implants. 15 patients (27.3%) required removal of 20 implants (15.5%) due to infection: five patients with occult infection (six implants) and one patient with low-grade infection (two implants). All infected implants were located in the paranasal region with the exception of one malar implant.

Conclusions: These findings demonstrate a clinically significant infection rate for facial implants in cleft patients, predominantly affecting the paranasal region. This likely relates to their proximity to the sinonasal cavity, compromised soft tissue in this region, and local biomechanical factors. Our data emphasise the importance of comprehensive patient counselling regarding site-specific infection risk and careful consideration of alternative approaches for paranasal augmentation.

Psychology in a 22q MDT: What Do Professionals Need, Notice, and Want Next?

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Background: Individuals with 22q11.2 deletion syndrome (22q) present with complex, intersecting psychological, behavioural and neurodevelopmental needs. Yet how MDTs understand and operationalise psychological input within 22q clinics remains under specified, risking unmet needs, fragmented liaison with community services, and variable pathways. Following additional funding for non-cleft VPD, our centre embedded psychology within a dedicated 22q MDT.

Aims and Objectives: This evaluation aimed to understand the impact and role of embedding psychology within a dedicated 22q MDT, seeking to:

- Clarify how psychological input is understood
- Assess the perceived impact of embedded psychology
- Identify gaps and barriers in pathways.
- Gather MDT priorities for how psychological support could be better targeted.
- Inform service improvement

Method: A 15-item mixed methods survey was distributed to all clinicians within the 22q MDT. Quantitative items were analysed descriptively; open-ended responses underwent inductive content analysis. The survey explored perceived psychological needs, adequacy of current provision, liaison with wider services, and priorities for development.

Results and conclusions: Professionals reported-

- A broad profile of psychological, behavioural and neurodevelopmental difficulties affecting individuals with 22q11DS and families.
- Barriers to access and liaison challenges with education, CAMHS/AMHS and community services.
- Unclear referral pathways and overlooked needs, especially around early identification and parenting support.
- Added value of embedded psychology-improved formulation, earlier recognition, and reduced stigma.
- Needs- clearer pathways, consultative support to upskill local teams, and shared resources.

In conclusion, embedding psychology within a 22q MDT enhances team functioning and access to timely psychological support. Recommendations include:

1. establishing clear referral and feedback pathways with mental health and education,
2. adopting a consultative model to build local capacity for recognition and management of psychological need,
3. developing shared resources for expectation setting and parenting support, and
4. involving families in ongoing evaluation and service design.

Cleft MDT Coordination Beyond Clinic Booking: Implications for Audit, Team Function, and Patient Experience

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Introduction: Cleft services rely on effective multidisciplinary team (MDT) working to deliver complex, longitudinal care. The cleft coordinator role is often perceived as primarily administrative; however, in practice it encompasses a broader range of clinical pathway, communication, and relational functions that are poorly defined and under-recognised.

Aims: To characterise the scope of the cleft coordinator role within a regional MDT and quantify activities undertaken beyond clinic booking, highlighting implications for team function, audit delivery, and patient experience.

Methods: A service evaluation was conducted using a structured "week-in-practice" role analysis. Coordinator activities were prospectively recorded over a representative working week and categorised into predefined domains including clinic coordination, audit and data management, MDT communication, patient and family liaison, and ad hoc problem-solving. Frequency and time allocation were reviewed, alongside qualitative description of tasks requiring sustained MDT involvement.

Results: Coordinator activity extended substantially beyond appointment booking. A significant proportion of time was dedicated to MDT communication, patient and family support, facilitation of clinical pathways, and resolution of service pressures across professional boundaries. Tasks frequently required detailed knowledge of patients, staff, and service processes developed through sustained MDT involvement. Audit and data responsibilities, including national cleft audit submission, were embedded within this wider coordination role rather than functioning as isolated administrative tasks. The coordinator acted as a consistent point of continuity for both patients and professionals, supporting efficient clinic function and cohesive team working.

Conclusions: The cleft coordinator role represents a complex, experience-dependent MDT role rather than a purely administrative post. Quantifying this extended scope highlights its contribution to patient experience, audit delivery, and team cohesion. Clearer recognition of this role is important for the effective functioning and sustainability of cleft services.

Do lateral incisors distal to the alveolar cleft worsen prognosis of alveolar bone grafting?

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Background: Upper lateral Incisors show great variation in development characteristics in cleft patients. Embryologically, upper lateral incisors develop from the premaxilla. In cleft patients they frequently develop distal to the alveolar cleft where they are often classed as supernumerary teeth and are hence routinely extracted. We investigate whether lateral incisors distal to the cleft are associated with worse alveolar bone grafting (ABG) outcomes based on Kindelan scores (KS).

Method: ABGs undertaken over 2 consecutive years (5 years of data will be available) in one UK cleft centre were analysed for lateral incisor position relative to the cleft and whether the tooth was extracted. Kindelan scores were analysed to investigate association between location of tooth, whether or not it was extracted and ABG outcome.

Results: Over 2 years, 54 patients had 59 ABGs (5 bilateral) who had Kindelan scores based on post-ABG radiographs. 36 of the ABG sites had a lateral incisor pre-ABG, 23 were missing.
100% of the ABGs with lateral incisors positioned medial (n=6) or distal (n=16) to the cleft which were not extracted scored KS 1. All of ABGs with lateral incisors medial to the cleft which were extracted scored KS 1. 70% (n=7) of the ABGs with lateral incisors distal to the cleft which were extracted had a KS of 1 and 30% (n=3) had a KS of 2.

Conclusion: All Kindelan scores revealed successful ABG outcomes and the position of lateral incisors which were not extracted did not appear to compromise ABG outcome. These results will be expanded to include 5-years' of data at the point of presentation. At present, these findings support the avoidance of routine extraction of lateral incisors positioned distal to the cleft with no other clinical indication.

Exploring Baclofen's Role in Velopharyngeal Function: Single Case with Cerebral Palsy and Submucous Cleft Palate

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Background: Baclofen, a GABA agonist, is widely used to manage muscle spasticity in cerebral palsy. While its systemic effects are well documented, its influence on velopharyngeal function and speech outcomes remains unclear.

Aims and Objectives: To explore the potential impact of Baclofen on velopharyngeal function and speech clarity through literature review and single-case observation.

Methods: A systematic search of multiple databases was conducted to identify evidence on Baclofen's effects on palatal function. Clinical data were collected from a child with cerebral palsy and submucous cleft palate using parental reports and the Great Ormond Street Speech Assessment (GOS.SP.AS) at three stages: before, during, and after Baclofen dose reduction.

Results: Literature review showed highly variable and unpredictable consequences in oral motor function with at times negative effect on speech production. No studies specifically addressed velopharyngeal mechanisMs In this case, parental reports indicated improved speech clarity during and after Baclofen reduction. GOS.SP.ASS demonstrated a mild increase in intraoral pressure and decreased nasal airflow symptoms, suggesting improved velopharyngeal closure with the reduction of Baclofen.

Conclusions: This case highlights a potential link between Baclofen dosage and velopharyngeal function, with implications for speech outcomes in patients with cerebral palsy and palatal anomalies. Clinicians should consider medication effects during assessment and treatment planning. Further research is needed to clarify this relationship and guide multidisciplinary care.

References: Kristie F. Bjornson, et al (2003), Leary S.M. et al (2006), Ghanavatian S, et al (2025).

Growing Up With a Cleft: What Children Know and How Families Understand

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Background: Cleft lip and/or palate care focuses on multidisciplinary management from infancy to adulthood. A key aim of this care model is to support patients and families in developing an understanding of the cleft condition and its treatment, enabling meaningful involvement in care and decision-making.

Despite this, individuals born with a cleft may reach adulthood with confusion or misinformation about their condition (Abualfaraj et al., 2019). Clinicians may assume that repeated exposure to cleft services results in adequate understanding; however, this may not always reflect patients' actual knowledge.

Understanding the health condition and being able to engage in shared decision making is fundamental for patient autonomy and informed consent. Gaps in knowledge during childhood may persist into adulthood. Ensuring that patients are knowledgeable about their condition is a key responsibility of cleft services.

Aims:

- Evaluate children's knowledge and understanding of their cleft at ages 5, 10 and 15 years
- Explore parental perceptions of their child's understanding of their cleft, parents self-rated knowledge of cleft and how comfortable parents felt discussing cleft with their child
- Determine whether demographic (including gender, ethnicity, religion, SEN status) and clinical factors are associated with differences in children's knowledge and understanding of their cleft

Method: Data was collected from 50 children and their families between October and March 2026. Children's knowledge was scored using a tiering system. Parents were also asked to rate their perception of their child's and their own understanding of the cleft, and how comfortable they felt speaking to their child about the cleft.

Results: Variation in children's understanding of their cleft at the 3 audit age groups will be discussed together with differences observed between parental perceptions of child's and parents understanding. Full analysis including associations with demographic and clinical factors will be presented.

Parental experience and burden of care associated with Koken nasal splints following cleft lip repair.

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Background: Koken nasal splints for post-operative cleft lip repair, came into use in the late 1980's & early 1990's following research by Dr Katsumi Matsuo & colleagues in Japan.

They are now used by various cleft surgeons globally to maintain the corrected position of the alar cartilages & direct postsurgical healing.

Patients following definitive unilateral or bilateral cleft lip repairs will have Koken splints inserted & sutured into the septum at the end of their operation. These splints or stents, as they are often referred, are ideally kept in-situ for 6 weeks post-operatively.

Aims/Objectives: To analyse the impact these splints have on parental experience of caring for their child in the 6 weeks post-op and the potential increased burden of care.
Previous studies have focused on clinical outcomes & less on burden of care.

Method: A retrospective study analysis of patients with unilateral and bilateral cleft lip +/- palate, under 1 surgeon at the Oxford site of the Spires Cleft network, born between 2019-2025.
This totalled 84 patients.
A questionnaire was filled in at 6 weeks post-op asking parents to score burden of care with stents on factors such as breathing, sleeping, feeding, responsibility and involvement in care. As well as views on nose shape.

Conclusions: The audit identified high satisfaction with nose shape & confidence in managing their child's stents.
It did however highlight difficulties in managing breathing, feeding and sleep and although parents reported high confidence in the care they gave their child, parents did report an implied burden of care associated with the responsibility put on them.
These factors need to be considered by the nursing team when preparing families for cleft lip repair and the support offered during recovery.

Co-production of a Non-Cleft VPD Referral Form: A Community and Cleft SLT Collaboration

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Introduction: Co-production is increasingly recognised as a key driver of quality improvement in healthcare (NHS England, 2023). Healthcare research indicates that tools developed collaboratively with staff are more usable, better adopted and more likely to meet real-world needs than top-down designs.

Additionally, in cleft care, best-practice guidance stresses timely referral and seamless communication between specialist teams and community speech and language therapists (SLTs) (Stock et al., 2022).

As community SLTs are often the first to identify children in the community with non-cleft velopharyngeal dysfunction (VPD), the co-production of a referral form should ensure essential clinical signs are captured and timely collaborative decision making is supported.

Aim: To co-produce a non-cleft VPD referral form with community SLTs

Method: A community SLT was identified as a representative from each of the 6 local Health Boards covered by the Welsh Centre for Cleft Lip and Palate.

Virtual meetings were held with Cleft SLTs and community SLTs to discuss the creation and priorities for a new referral form.

A thematic analysis of meeting transcripts identified recurring themes regarding content and structure.

Informal feedback was gathered from community SLTs during the creation of the referral form.

Results: Themes highlighted practical barriers and design priorities. Community SLTs reported feeling inexperienced to complete sections requiring specialist judgment and noted confidence gaps, especially among newer staff. Participants emphasised the need for supportive tools (e.g. step-by-step guides, visuals) and flexibility.

Overall, therapists wanted a referral form that was accessible, confidence-building, and focused on essential clinical signs without requiring full assessment.

Conclusion: The referral form was developed in direct response to the themes identified during analysis. It will be shared across all local health boards and piloted for 12 months, after which feedback will be collected to inform refinement and wider implementation.

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