# Making it better

22 January 2026

Craig Russell & Kate Fitzsimons

On behalf of the CRANE Database team

Overview

- Welcome and introductions

- 2025 Annual Report

  - Overview of data completeness and outcomes by report year & year of birth

  - New features of the report, including risk adjustment & outlier process

  - Good practice recommendations from outlier responses

  - Organisational Audit summary

- Shared learning relating to good practice and challenges (8 speakers)

- Q&A session

- CRANE Database developments

Welcome & introductions
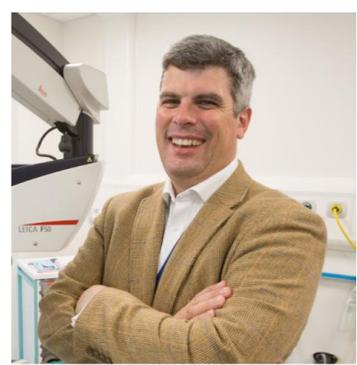
Craig Russell

Clinical Project Lead

Consultant Cleft, Plastic and
Reconstructive Surgeon, NHS
Greater Glasgow and Clyde

Kate Fitzsimons

Senior Research Fellow,
Clinical Effectiveness Unit, RCS

Samriddhi Sharma

CRANE Coordinator

Clinical Effectiveness Unit, RCS

Abhishek Dixit

Data Manager/Data Scientist,
Clinical Effectiveness Unit, RCS

2025 Annual Report

- Published December 2025
  - Key findings & recommendations
  - Registry information
  - Consent verification
  - 5-year outcomes
  - Summary of organisational audit
- Infographic
- Supplementary tables
- Outlier responses
- Summary for cleft community

RCS CRANE
CLEFT REGISTRY & AUDIT NETWORK
Promoting excellence in cleft care

Cleft Registry and Audit NEtwork Database
Part of the Clinical Effectiveness Unit, of the Royal College of Surgeons of England

2025 Annual Report
Results of the registry and audit for children born with a cleft lip and/or palate in England, Wales, Northern Ireland and Scotland

On behalf of the Cleft Development Group

Royal College of Surgeons of England
ADVANCING SURGICAL CARE

Annual Report 2025

CRANE is a national registry and clinical audit. It evaluates and reports on the delivery of cleft services to children born with a cleft lip and/or palate in England, Wales, Northern Ireland and Scotland. Registry information is presented for children born in 2022-2024 and audit outcomes at 5 years of age are presented for children born in 2016-2018.

Registry information

25,862 children have been registered since CRANE started in 2000.

901 children were born with a cleft in 2024.

78% of babies with cleft lip were diagnosed antenatally, while 74% of babies with cleft palate alone were diagnosed within 24hrs of birth.

82% were referred to a cleft team within 24hrs of birth and 97% were contacted within 24hrs of referral.

Distribution of cleft type

CP 43%	CL 26%	UCLP 20%	BCLP 9%	SMCP <2%	SMCP+CL <1%

Soft palate 32% Soft + hard palate 68%

Key: Cleft palate (CP), Cleft lip (CL), Unilateral/bilateral cleft lip and palate (UCLP/BCLP), Submucous cleft palate (SMCP)

90% of families had a verified consent status, 97% consented and 3% declined consent.

Audit outcomes at 5 years of age

Body mass index
84% of children with a cleft had a healthy BMI. 4% were underweight, 8% were overweight and 5% were obese.

Dental health
61% of children with a cleft had no decayed, missing or filled teeth. This compares to 71% of their non-cleft peers.

Facial growth
54% of children with a complete unilateral cleft lip and palate (UCLP) had scores reflecting good dental arch relationships.

Speech
54% of children with a cleft palate (+/-cleft lip) had speech comparable to their peers.
74% achieved speech without evidence of structurally-related speech difficulties.
62% achieved speech without cleft-related speech characteristics that may require therapy or surgery.
Speech varies according to cleft type.

Psychology
92% of children were seen by a psychologist. A psychological screen was completed or psychological input arranged if needed.

Development work

Organisational Audit Report
100% of cleft services responded to the first comprehensive organisational audit (OA) of cleft care since the CSAG report in the late 1990s.
The OA findings highlight considerable variation in commissioned services, staffing levels, and access to diagnostic and operative facilities.
A well-resourced and consistent model of cleft care delivery is required in the UK.
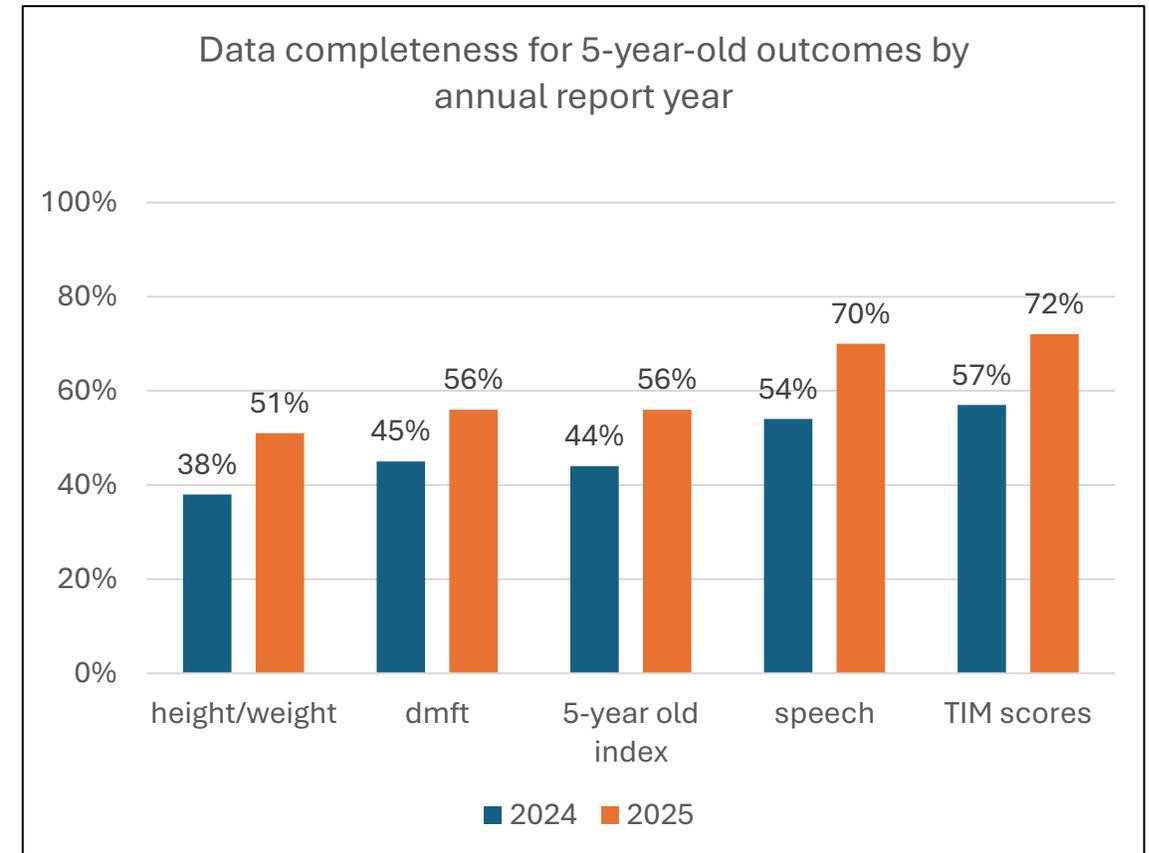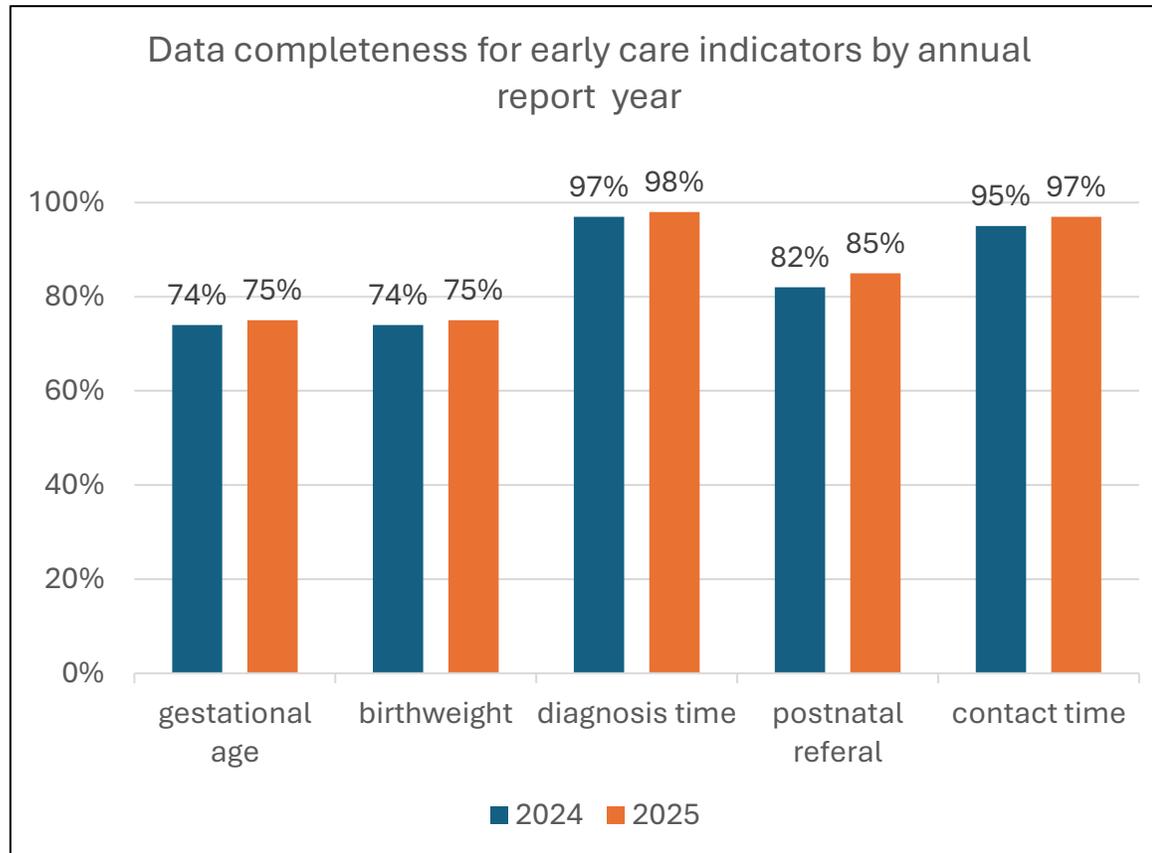
Conference Presentations
CRANE was involved in **7** different presentations across both the 15th International Congress of Cleft Lip/ Palate and Related Craniofacial Anomalies (**CLEFT2025**) in Japan and the Craniofacial Conference (**CFSGBI 2025**) in Newcastle.
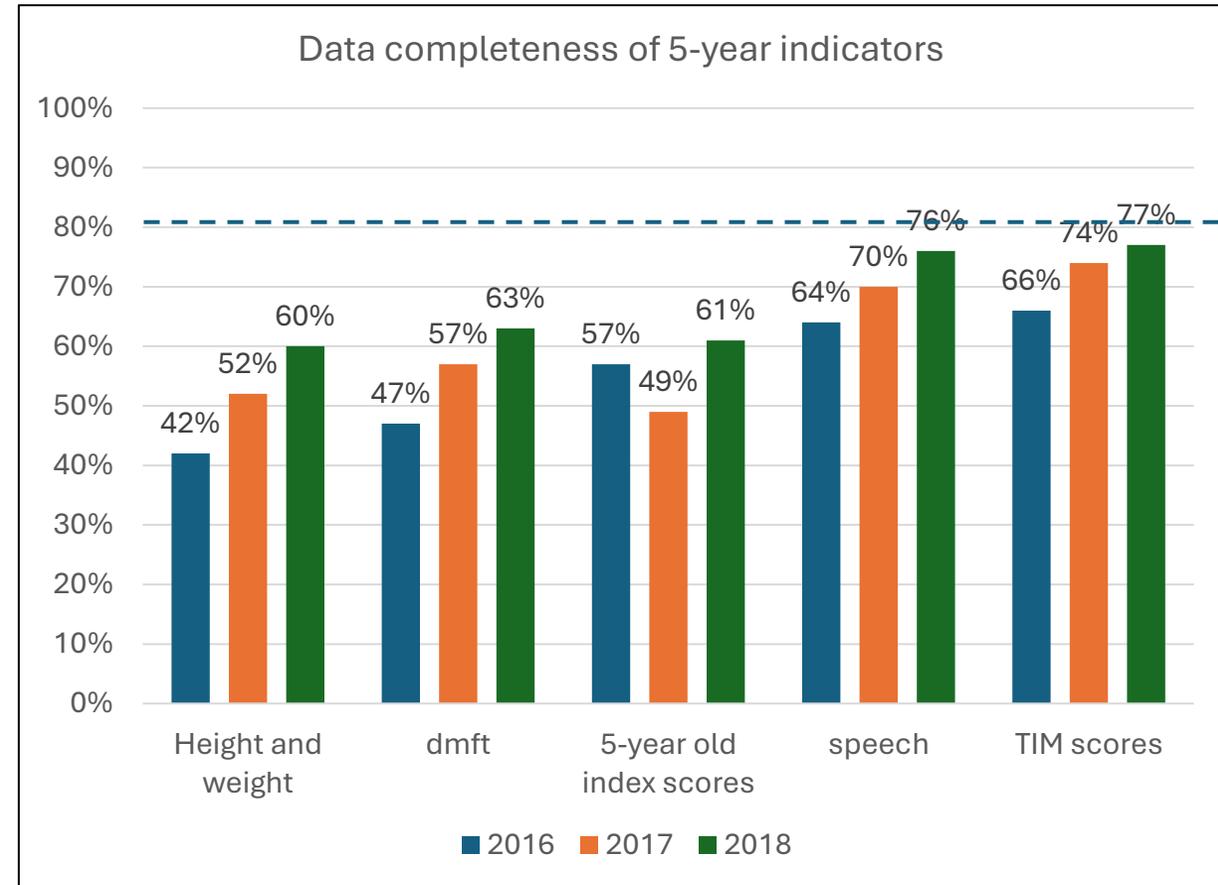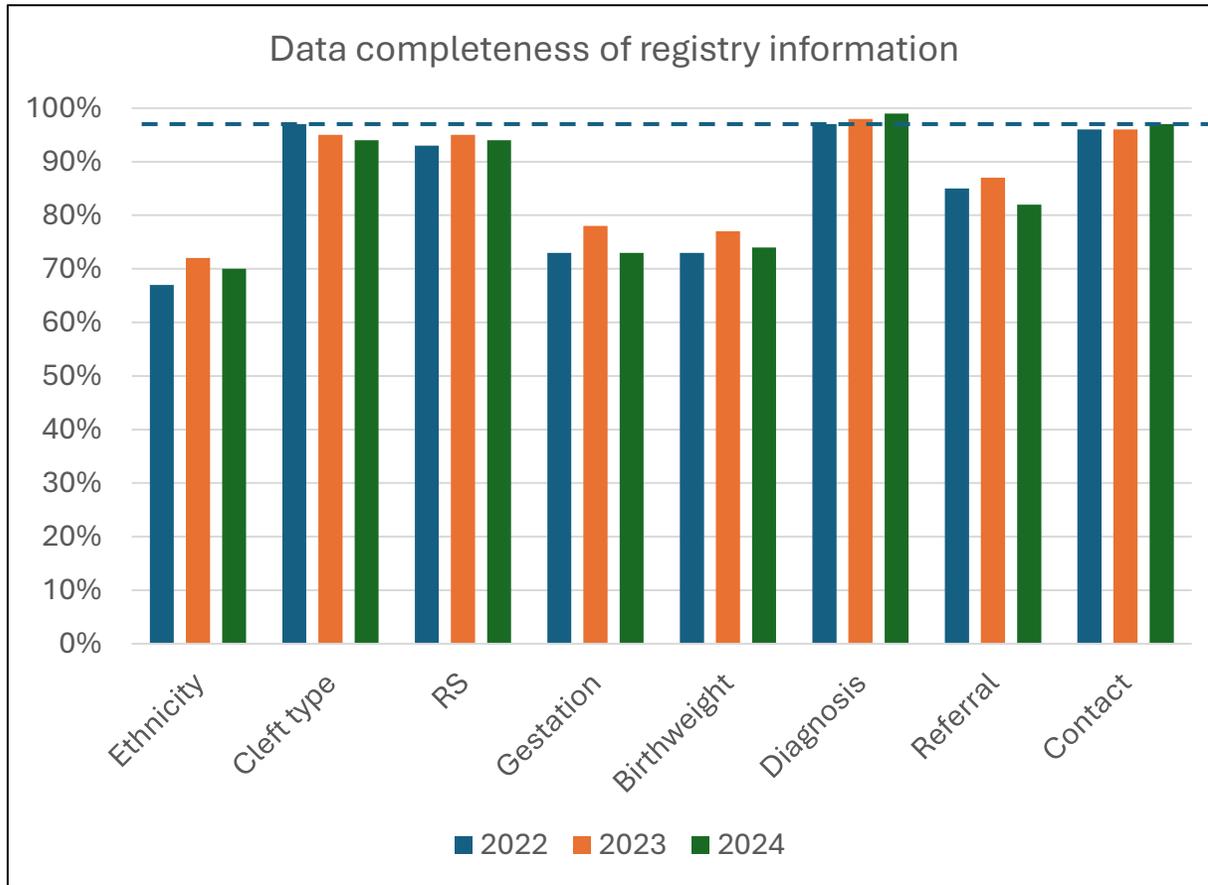We value sharing our findings with health professionals and patient representatives.

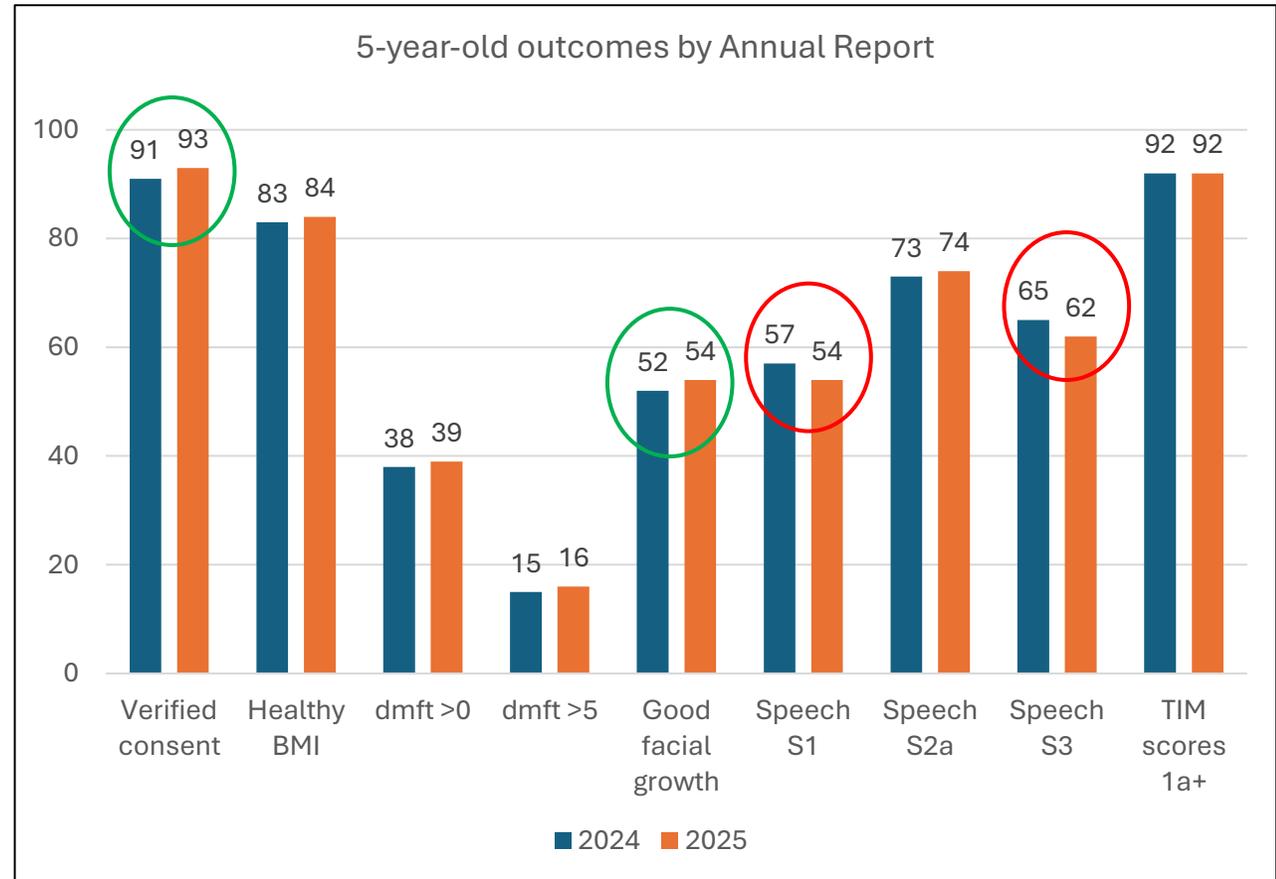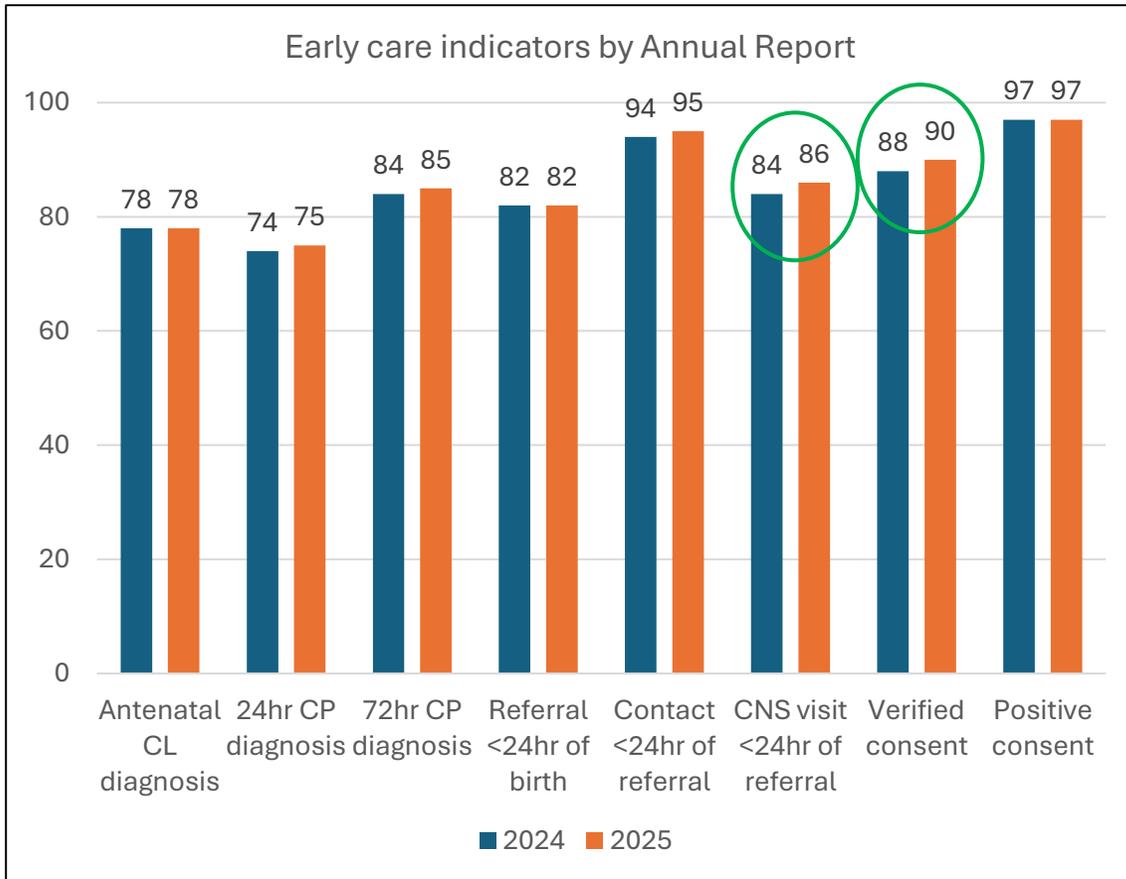For further information visit www.CRANE-Database.org.uk

Data completeness: Comparison with 2024 report

Data completeness for early care indicators by annual report year

Indicator	2024	2025
gestational age	74%	75%
birthweight	74%	75%
diagnosis time	97%	98%
postnatal referal	82%	85%
contact time	95%	97%

Data completeness for 5-year-old outcomes by annual report year

Outcome	2024	2025
height/weight	38%	51%
dmft	45%	56%
5-year old index	44%	56%
speech	54%	70%
TIM scores	57%	72%

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Data completeness by year of birth

Outcomes: Comparison with 2024 report

Early care indicators by Annual Report

Indicator	2024	2025
Antenatal CL diagnosis	78	78
24hr CP diagnosis	74	75
72hr CP diagnosis	84	85
Referral <24hr of birth	82	82
Contact <24hr of referral	94	95
CNS visit <24hr of referral	84	86
Verified consent	88	90
Positive consent	97	97

5-year-old outcomes by Annual Report

Outcome	2024	2025
Verified consent	91	93
Healthy BMI	83	84
dmft >0	38	39
dmft >5	15	16
Good facial growth	52	54
Speech S1	57	54
Speech S2a	73	74
Speech S3	65	62
TIM scores 1a+	92	92

5-year-old outcomes by year of birth
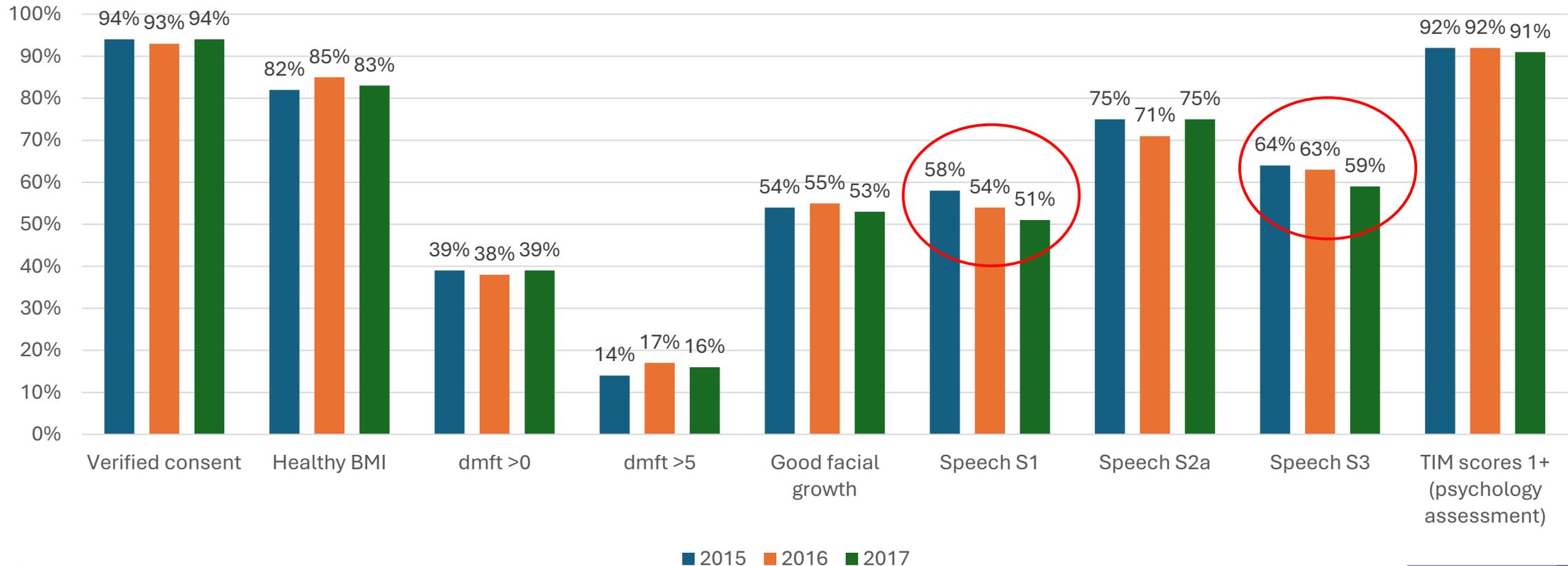
New features in the 2025 Annual Report

- **Ethnicity:** Reported for registry cohort and 5-year outcomes assessed for differences between white & ethnic minority groups

- **Antenatal contact/visit time:** Included in report

  - Cleft service range: 54%-100% visited within 24h of antenatal referral

- New supplementary table tab: **Data completeness and outcomes by patient characteristics** (birth year, cleft type, sex & ethnic group).

- **Transfers**: 61 children transferring care between 2 months & 5 years excluded from service-level reporting due to potential differences in outcomes.

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New features: speech standards 2b, 2c, 2d

Table 3 of 5: Speech standard 2b, 2c and 2d: VP Surgery/fistula repair status and evidence of structurally related issues, according to Cleft Service

Cleft Service	Eligible children with speech reported**	VP Surgery/fistula repair		S2b. No evidence of a structurally related issue after surgery		S2c. Evidence of a structurally related issue after surgery		No VP Surgery/fistula repair		S2d. No surgery but evidence of a structurally related issue	
		N	%	n	%	n	%	N	%	n	%
Newcastle	77	5	6.5%	2	40.0%	3	60.0%	72	93.5%	5	6.9%
Leeds	87	13	14.9%	3	23.1%	10	76.9%	74	85.1%	21	28.4%
Liverpool	94	30	31.9%	16	53.3%	14	46.7%	64	68.1%	9	14.1%
Manchester	96	16	16.7%	13	81.3%	3	18.8%	80	83.3%	12	15.0%
Trent	146	6	4.1%	4	66.7%	2	33.3%	140	95.9%	12	8.6%
West Midlands***	117	18	15.4%	9	50.0%	9	50.0%	99	84.6%	14	14.1%
Cleft Net East	94	13	13.8%	7	53.8%	6	46.2%	81	86.2%	11	13.6%
North Thames	141	15	10.6%	8	53.3%	7	46.7%	126	89.4%	34	27.0%
Spires	103	11	10.7%	7	63.6%	4	36.4%	92	89.3%	9	9.8%
South Wales	54	11	20.4%	9	81.8%	2	18.2%	43	79.6%	3	7.0%
South West***	57	10	17.5%	4	40.0%	6	60.0%	47	82.5%	13	27.7%
Evelina London***	112	20	17.9%	14	70.0%	6	30.0%	92	82.1%	10	10.9%
Northern Ireland	33	8	24.2%	5	62.5%	3	37.5%	25	75.8%	4	16.0%
Scotland***	93	12	12.9%	8	66.7%	4	33.3%	81	87.1%	8	9.9%
Total	**1,304**	**188**	**14.4%**	**109**	**58.0%**	**79**	**42.0%**	**1,116**	**85.6%**	**165**	**14.8%**
Revised totals***	925	128	13.8%	74	57.8%	54	42.2%	797	86.2%	120	15.1%

* Registered in CRANE by 30 June 2025.

** Exclusions: (1) children who died before the age of 5 years, (2) children with a submucous cleft palate, (3) children with a diagnosed syndrome entered onto the CRANE Database, and (4) children who transferred cleft care between 2 months and 5 years of age.

% [Green highlight]   Most desirable rate
% [Pink highlight]   Least desirable rate

New features: risk adjustment

Risk adjustment of service-level outcomes introduced for speech & dental

- Some units see:
  - More babies with additional medical conditions
  - More severe clefts
  - More boys than girls
  - More children from areas with higher deprivation

- These factors affect outcomes *before* any treatment happens. CRANE adjusts for them so that differences between services reflect **care quality**, not **patient mix**.

- Adjustment tries to level the playing field
  - Risk-adjustment is never perfect
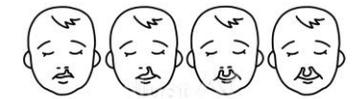
Risk adjustment process

Step 1: Multiple imputation of missing data for patient characteristics included in model

Step 2: Estimate each child's expected outcome

Using national data, CRANE calculates the *expected* chance of a particular outcome for each child, based on their characteristics.

Step 3: Compare expected vs actual outcomes

For each cleft centre, CRANE looks at:

- how many children were *expected* to have a particular outcome
- how many *actually* had a particular outcome

Step 4: Produce adjusted centre-level results, presented in funnel plots

This allows CRANE to say whether a centre is performing:

- better than expected (**positive outlier**)
- as expected (within funnel)
- worse than expected (**negative outlier**)
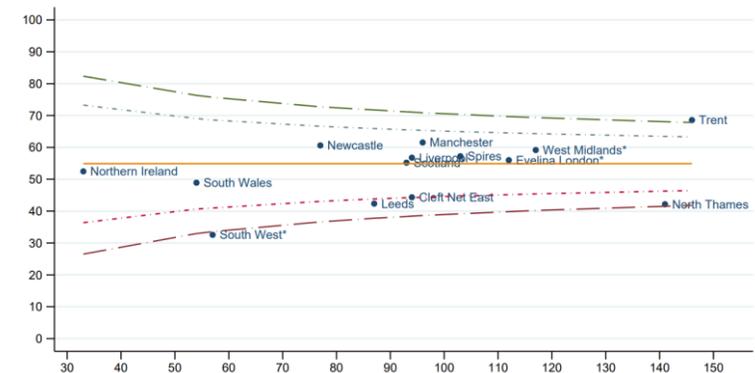
Risk adjusted outcomes

Dental dmft

- Deprivation based on postcode
- Country (due to country-specific indexes for deprivation)
- Robin Sequence status
- Cleft type
- Extent of palate involvement

Speech standards 1, 2a and 3

- Cleft type,
- Extent of hard palate involvement
- Robin Sequence status
- Sex

Unadjusted & adjusted rates: dental caries

Unadjusted dmft >0
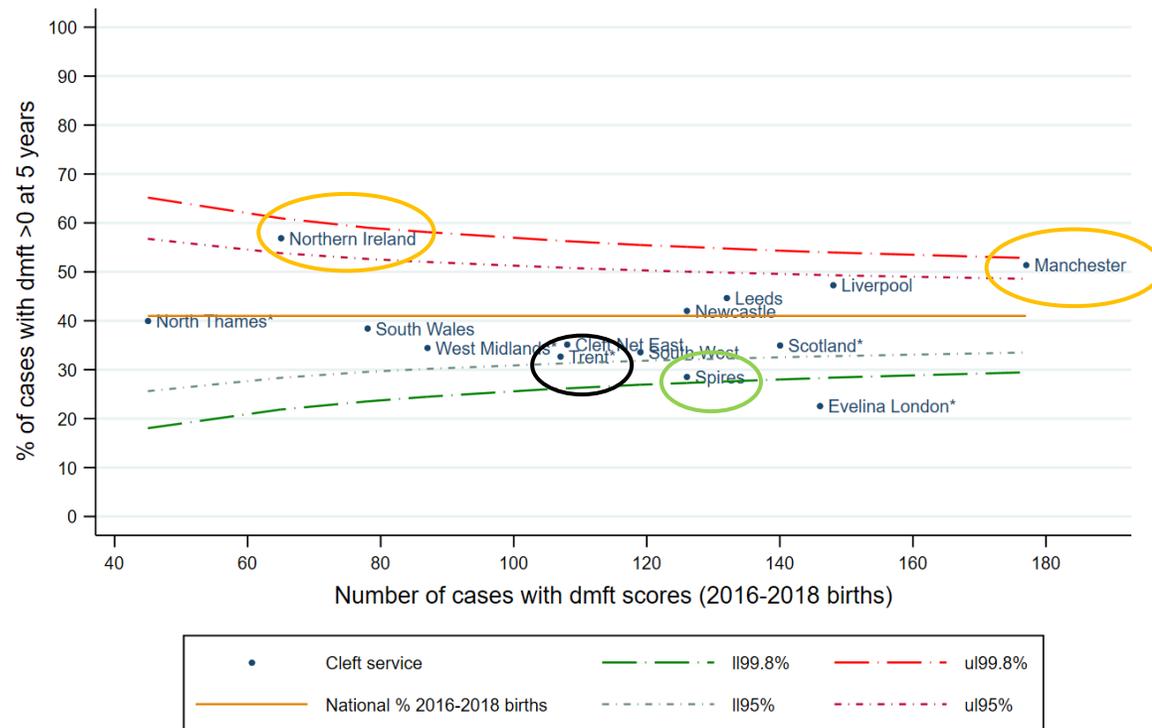
Adjusted dmft >0

Extensive caries

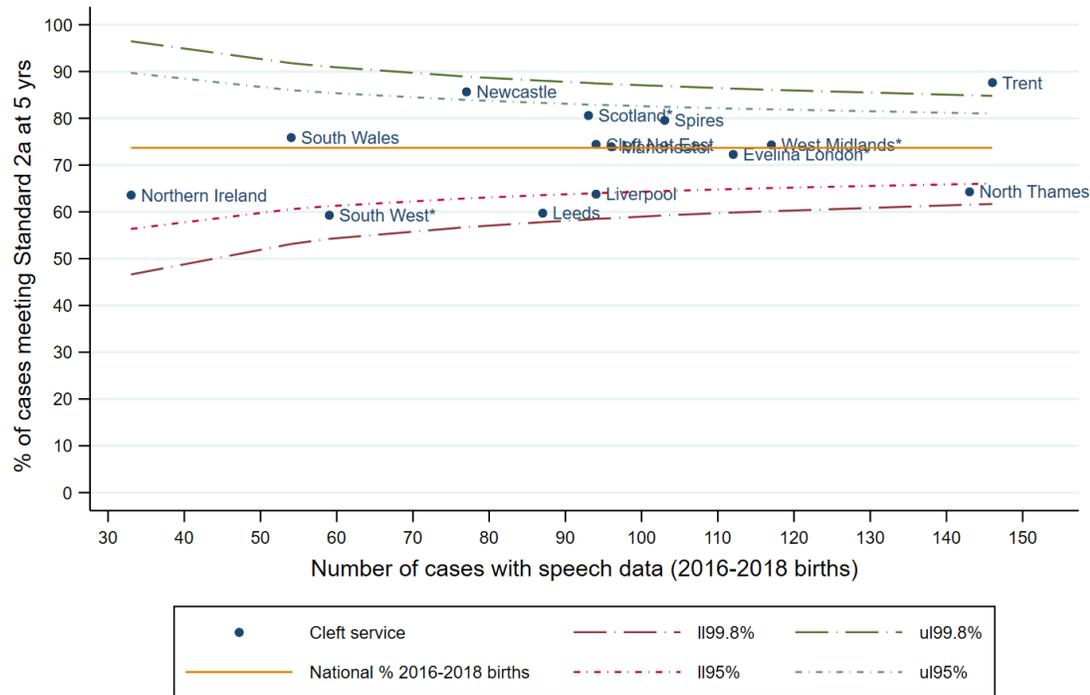
Unadjusted dmft >5
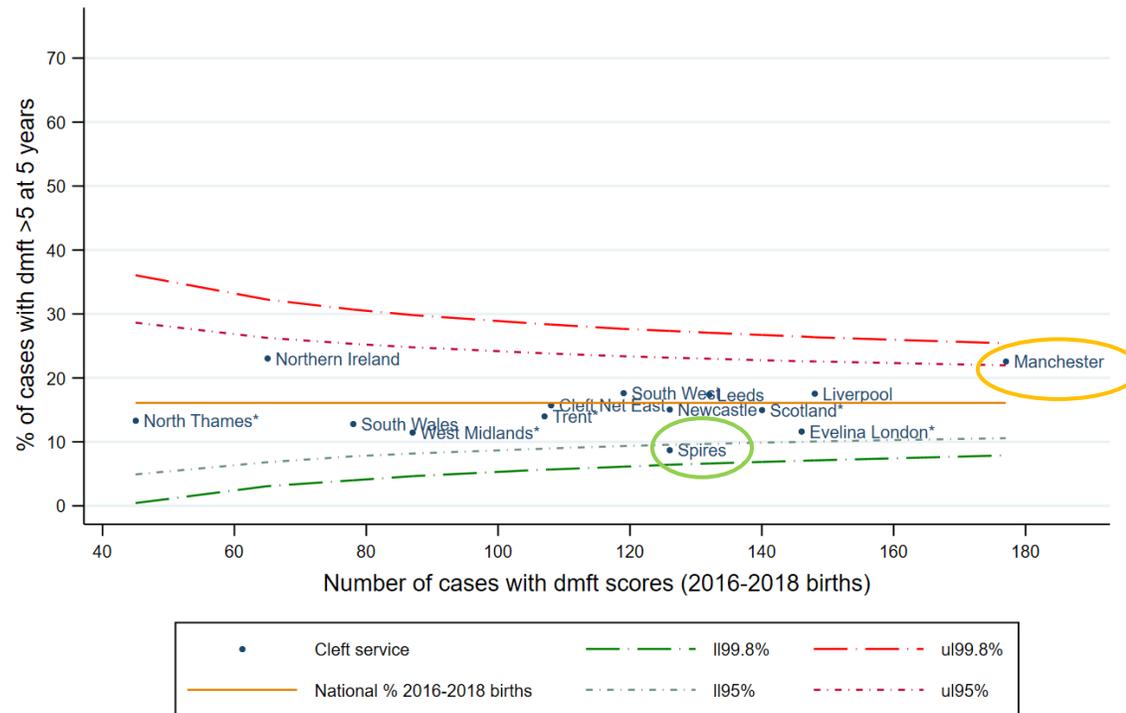
Adjusted dmft >5

Note 1. Data from Scotland and West Midlands were not used to create funnel plot due to poor consent verification rate.
Note 2. Data from Trent, West Midlands, North Thames & Evelina London were not used to create funnel plot due to poor data completion rates.
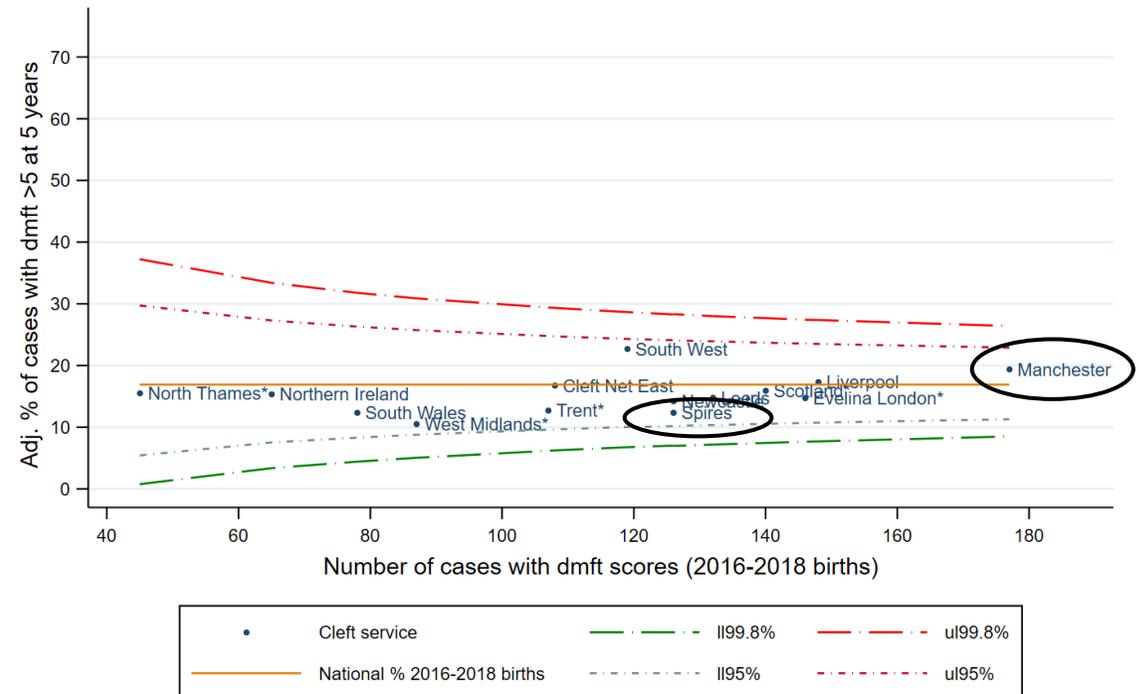
Note 1. Data from Scotland and West Midlands were not used to create funnel plot due to poor consent verification rate.
Note 2. Data from Trent, West Midlands, North Thames and Evelina London were not used to create funnel plot due to poor data completion rates.
Note 3. Adjusted for deprivation quintile, country, prs status, cleft type, extent of palate involvement and sex
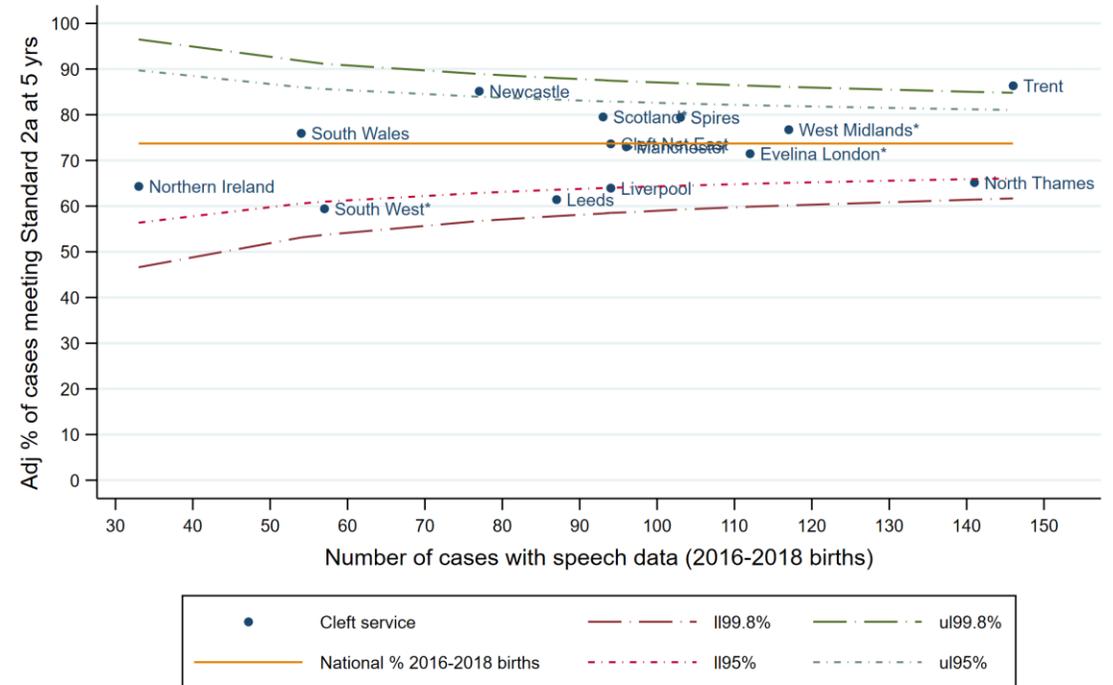
Speech standard 1: normal speech

Unadjusted speech standard 1

Adjusted speech standard 1

Speech standard 2a: No structurally related speech difficulties

Unadjusted speech standard 2a

Adjusted speech standard 2a

Speech standard 3: No cleft-related articulation difficulties

Unadjusted speech standard 3

Adjusted speech standard 3

New features: Outlier policy

- Formal introduction this year
- Indicators subject to outlier policy:
  - Consent verification (2016-2018 births)
  - Data completeness & outcomes at 5 years (2016-2018 births):
    - Growth
    - Dmft >0 & dmft>5
    - 5-year old index
    - Speech standards x3
    - Psychology Tiers of Involvement Measure scores

Outlier policy implementation

Cleft Registry and Audit NEtwork (CRANE) OUTLIER POLICY PROCESS TIMELINE 2025
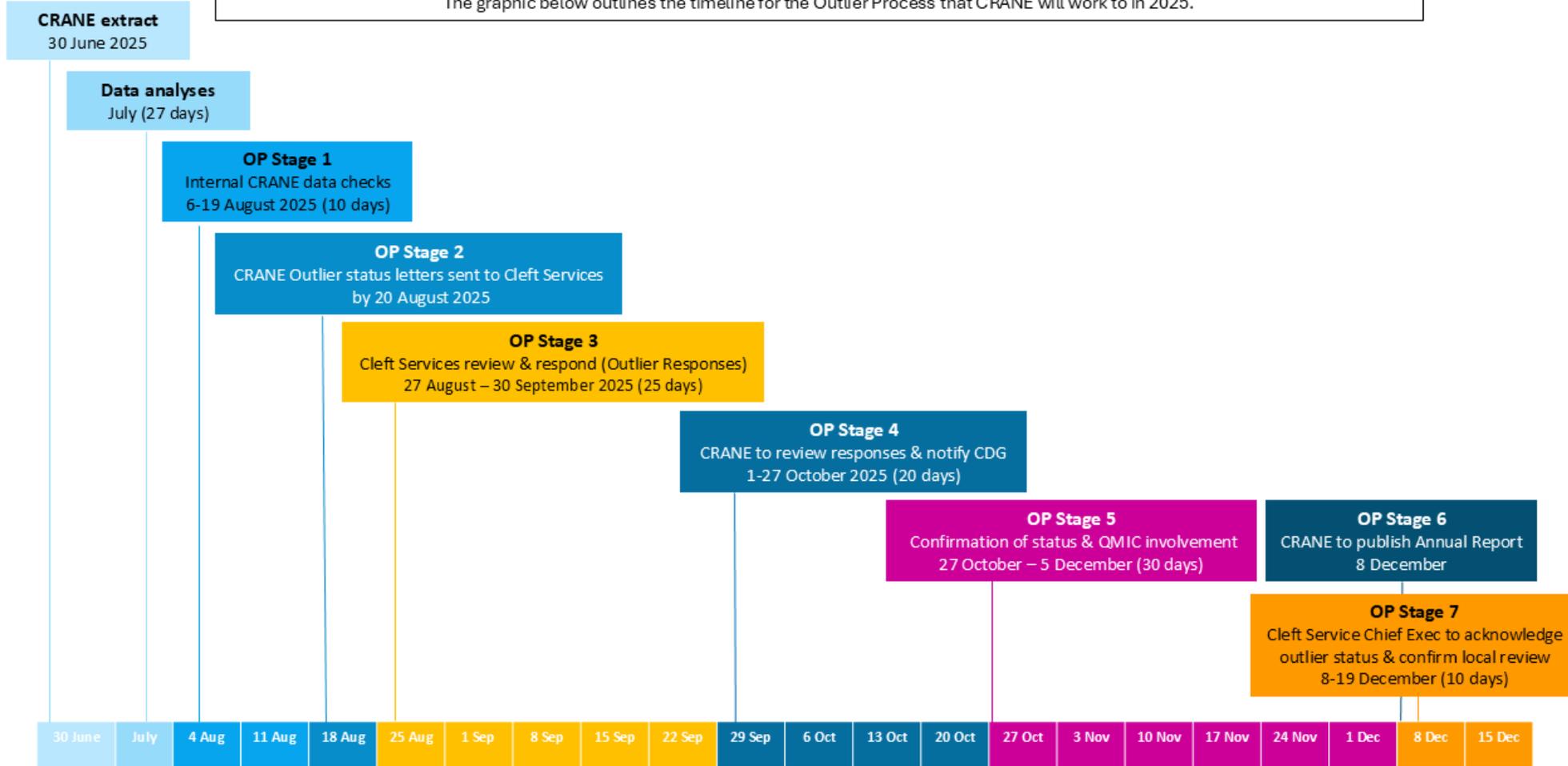The graphic below outlines the timeline for the Outlier Process that CRANE will work to in 2025.

CRANE extract
30 June 2025

Data analyses
July (27 days)

OP Stage 1
Internal CRANE data checks
6-19 August 2025 (10 days)

OP Stage 2
CRANE Outlier status letters sent to Cleft Services
by 20 August 2025

OP Stage 3
Cleft Services review & respond (Outlier Responses)
27 August – 30 September 2025 (25 days)

OP Stage 4
CRANE to review responses & notify CDG
1-27 October 2025 (20 days)

OP Stage 5
Confirmation of status & QMIC involvement
27 October – 5 December (30 days)

OP Stage 6
CRANE to publish Annual Report
8 December

OP Stage 7
Cleft Service Chief Exec to acknowledge
outlier status & confirm local review
8-19 December (10 days)

| 30 June | July | 4 Aug | 11 Aug | 18 Aug | 25 Aug | 1 Sep | 8 Sep | 15 Sep | 22 Sep | 29 Sep | 6 Oct | 13 Oct | 20 Oct | 27 Oct | 3 Nov | 10 Nov | 17 Nov | 24 Nov | 1 Dec | 8 Dec | 15 Dec |

May 2025

Outliers: All fourteen services received letters

All indicators (data completeness & outcomes)

- Positive outlier status only: 2 services

- Mixed positive and negative status: 10 services

- Negative outlier status only: 2 services

5-year outcome indicators only: dental, speech & psychology

- Positive outlier status only: 5 services

- Mixed positive and negative status: 1 service

- Negative alert only: 3 services

- Negative outlier status only: 5 services

Learning from positive outlier responses

- All services responded to outlier notification

- Published alongside report

- Reviewed responses from high-performing cleft services

- Summarised key recommendations to support quality improvement

    1. Data completeness

    2. Clinical outcomes

Data completeness: good practice

1. Establish dedicated roles and processes

- Dedicated data coordinators / admin support
  - Recruit or secure funding for full admin cover of data tasks - build business cases for admin posts using CRANE performance data
- Cross-cover data roles to reduce risk
- Protected audit time in job plans (nursing, admin, SLT, psychology)
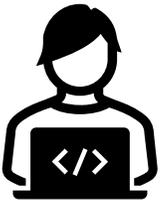
2. Integrate data collection into clinical workflows

- Preprepared consent packs and prompts to improve consent verification
- Data collection embedded in MDT clinics

3. Continuous monitoring and integrated systems

- Monitor completeness regularly - extract routine data snapshots for internal review meetings
- Use integrated clinical and audit systems to flag outstanding consent & missing entries quickly
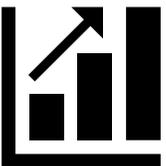
Note: where services struggled with missing data, lack of staffing was major factor

Dental: good practice

What High Performers Did Well

- Paediatric dental team consistently attends 5-year audit clinics, including spoke sites.

- Active follow-up for non-attenders to secure dmft data.

- Centralised audit clinics used by some services to maximise robust data collection.

- Specialist/trainee dental support boosts performance and care indices.

Speech: good practice

What High Performers Did Well

- Evidence-based surgical procedures + early outcome markers drive improvement

- Early and repeated speech assessment embedded into care pathways

- Close SLT-surgeon collaboration for early interventions

- Long-term MDT culture of audit, shared learning and continuous improvement

- Participation in national calibration

Psychology TIM1+ scores: good practice

What High Performers Did Well

- Dedicated psychology staffing with protected audit responsibilities

- Psychology consistently present at MDT audit clinics, enabling timely screening

- Proactive identification and invitation of eligible children to audit clinics

- Regular validation of TIM scoring to correct inaccurate zero scores
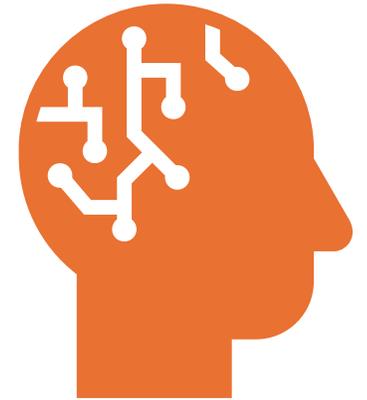
Overview of Organisational Audit findings

Service Structure and Configuration

- 100% response rate from all Cleft Services

- 60% of services led by surgeons

- Most services operate across multiple sites (average: 5 sites)

- Wide variation in commissioned services, staffing levels, and access to diagnostic and operative facilities

Funding and Sustainability

- Many services deliver unfunded elements of care, raising concerns about long-term sustainability

- Inequity exists between services in terms of WTE (funded + unfunded) staff members and new cleft cases

- Workforce shortages common, particularly in **Psychology, Orthodontics** and **Paediatric dentistry**

Equity of Access

- Ongoing challenges in equitable access across geography and specialties

- **Paediatric dentistry** and **speech & language therapy** are areas of particular concern

CRANE Organisational Audit Report 2025 - CRANE Database

Cleft Registry and Audit NEtwork Database

Organisational Audit Report

An Organisational Audit of services providing care to children born with a cleft lip and/or palate in England, Wales, Northern Ireland and Scotland

Published 18 July 2025
On behalf of NHS England and the Cleft Development Group

Figure 8. Service-level total WTE staff according to new cleft cases born in 2024 (CRANE registrations). Each marker represents a responding cleft service
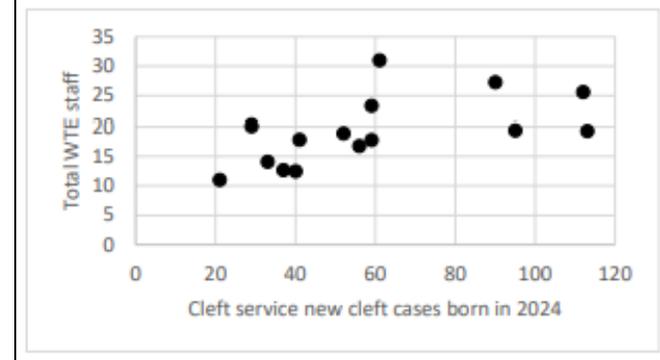
Organisational Audit

Detection, Referral, and Early Care

- 80% of services reported concerns about delayed detection or referral of clefts

- Only 40% felt adequately funded to train external professionals (e.g., midwives, health visitors)

Surgical Timelines

- Most services aim to repair:
  - Lip by 3–4 months
  - Palate by 9 months

- However, 33% reported delays to these timings during 2024

Use of the CRANE Database

- High levels of engagement with CRANE

- CRANE valued for:
  - Benchmarking
  - Quality improvement
  - Supporting service development

Figure 19. Service-level theatre sessions per month plotted against new cleft cases born in 2024 (CRANE registrations). Each marker represents a cleft service
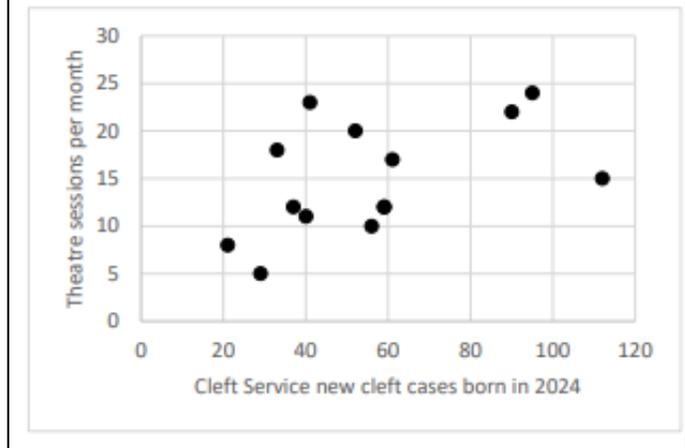
Organisational Audit conclusion

- Unique resource when combined with Annual Reports

- Early improvements have remained relatively static

- Significant variation in cleft care delivery

- Significant variation in outcomes

- Much more can be achieved by learning from the most efficient and effective services

- WEE can do it together!

Learning from good practice
Invited speakers

Early diagnosis

Updated guidance from RCPCH

6 Key recommendations

1. Healthcare professionals should examine an infant's hard and soft palate as part of Newborn and Infant Physical Examination (NIPE) and record this in the SMaRT4 NIPE (S4N) live system or GP IT system.

2. Examination of an infant's palate should be carried out by visual inspection.

3. A torch and method of depressing the tongue should be used to visualise the whole palate.

4. Parents should be informed if the whole palate (including the full length of the soft palate) has not been visualised during the NIPE.

5. If the whole palate is not able to be visually inspected at first attempt then a further attempt at visual examination should be made within 24 hours.

6. Trusts should provide training on the correct method of visual inspection of the palate to all healthcare professionals required to carry out the NIPE.

Palate examination: Identification of cleft palate in the newborn - best practice guide | RCPCH

Palate examination: Identification of cleft palate in the newborn and infant

Best practice guide

November 2025

Cleft Palate Diagnosis in Scotland

Jenny Pettigrew
Cleft CNS Lead

2022-2024 births

- 80% diagnosed <24 hours of birth
- 90% diagnosed < 72 hours of birth

- Scotland has 14 healthboards
- Babies can be delivered in 47 hospitals (29 midwife led units).

What do we do – Raising Awareness

- Hospital teaching

- University teaching (pre reg midwives, post reg - neonatal course, HV)

- NHS Education for Scotland (NES) webinar (also recorded and available to watch on demand).

- Virtual session with national group for infant feeding advisors

- Link in each unit, we contact yearly to offer teaching, send updated information.

- Share case studies with photos
- Share lived experience through video and open letter.
- Use palate moulds
- Encourage RCPCH e-learning module detecting cleft palate early

Feedback

- Feedback to unit when cleft palate diagnosis late, offering teaching.

One hospital now has a face to face teaching session every 6 months, with rotation of medical staff

- Questions?

CRANE: Making it Better

Diagnosis of cleft palate within 72 hours of birth

Emma Glass – Lead CNS
Kate le Maréchal – Head of Service

21 January 2026

Table 1 of 2: Number of CRANE-registered* children born with a cleft palate alone (CPO) in 2022-2024, according to diagnosis time and Cleft Service (Excludes babies born <34 weeks' gestation)

Cleft Service	Antenatal or <24 hours after birth		Alert or outlier (not subject to outlier policy)**	2024 AR outlier status	Antenatal or <72 hours after birth		Alert or outlier (not subject to outlier policy)**	2024 AR outlier status
	n	(%)			n	(%)		
Newcastle	34	60.7%	Negative alert		39	69.6%	Negative alert x2	Negative alert
Leeds	44	81.5%			47	87.0%		
Liverpool	48	81.4%		Positive alert	52	88.1%		
Manchester	43	76.8%			51	91.1%		
Trent	68	71.6%			74	77.9%		
West Midlands**	64	79.0%		Positive outlier	70	86.4%		Positive alert
Cleft Net East	54	69.2%			68	87.2%		
North Thames	85	66.9%			103	81.1%		
Spires	60	70.6%			68	80.0%		
South Wales	31	81.6%			33	86.8%		
South West	54	74.0%			62	84.9%		
Evelina London	88	78.6%			104	92.9%	Positive alert	
Northern Ireland	31	79.5%			35	89.7%		
Scotland	77	82.8%		Positive alert	84	90.3%		
Total	**781**	**74.7%**			**890**	**85.1%**		
Revised total	717	74.3%			820	85.0%		

Detection within 72 hours of birth	
What did we find?	• 85% of children with a cleft affecting the palate alone (excluding SMCP alone) were diagnosed before or within 72 hours of birth (Cleft Service range: 70%-93%, p=0.008). This represents minimal change compared to the previous reporting period (2021-2023 births). • 72-hour diagnosis rates varied significantly according to extent of cleft involvement (LAHSAL codes 's': 71%, 'S': 83%, 'Sh': 86%, 'SH': 91%, p<0.001), but not according to birth year (p=0.176), sex (p=0.067) or ethnicity (p=0.338). • 41% of children with a SMCP alone were diagnosed within 72 hours of birth.
Outliers	Positive outlier: None Negative outlier: Newcastle* (70%) *Negative alert status for two consecutive reporting periods and therefore classed as outlier.

Figure 3.8. Funnel plot showing the percentage of CRANE-registered children with a cleft affecting the palate alone (excluding SMCP), born ≥34 weeks' gestation from 2022 to 2024, who were diagnosed before or within 72 hours of birth, according to Cleft Service.
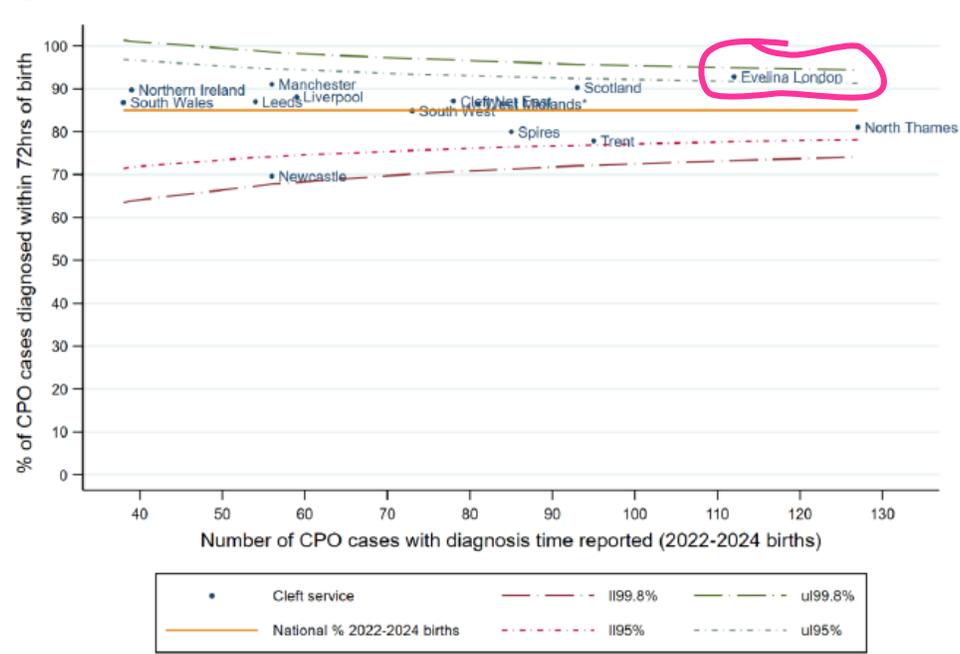
Note: Funnel plot centred on the revised national percentage (85.0%) of children (born 2022-24) diagnosed antenatally or <72 hours after birth.

Diagnosis of cleft palate within 72 hours of birth

WHY?

1. **Cleft is "on the radar" across our patch**
   Strong, longstanding relationships with maternity, foetal medicine and neonatal teams mean that cleft is actively looked for and flagged early. Staff know who we are and how to reach us.

2. **Routine reinforcement of palate examination skills**
   We invest in refresher training for midwives and neonatal staff, particularly around confident examination of the palate. This includes:
   - targeted teaching following any "missed baby"
   - visual prompts (posters, cards)
   - embedding palate examination into newborn documentation and proformas

3. **Low-threshold referral culture**
   Our message is simple: *if in doubt, refer.*
   Enquiries are welcomed and never criticised or "bounced", which reduces hesitation and delay.

Diagnosis of cleft palate within 72 hours of birth

4. **Systems that support rapid confirmation and recording**
   Once a baby is flagged, our pathways enable timely specialist assessment and prompt CRANE entry.
   Good data capture both reflects – and reinforces – timely diagnosis.

5. **Crucially: a CNS service that works weekends**
   Babies born or identified on a Friday do not have to wait until Monday.
   Weekend CNS cover means that suspected cleft palate can be assessed, confirmed and recorded within the 72-hour window.

HAVE YOU CHECKED FOR A CLEFT?

The palate AND uvula MUST be visualised as part of the newborn examination.

- **DO NOT** finger 'sweep' or only palpate the palate. Use a torch and a tongue depressor to visualise the soft and hard palates as well as the uvula.
- Diagnosis after 72hrs of life is classified as a delayed diagnosis.
- Each year 10-20% of children receive a delayed diagnosis of cleft palate.
- A delayed diagnosis has implications for the child (feeding issues, faltering growth, increased hospital stays, unnecessary investigations, speech & hearing delays) and parents (increased anxiety, loss of trust in health professionals, potential litigation issues).
- The Cleft Team will contact parents within 24 hours of receipt of a referral to offer information & support to the family and healthcare team.

UNDERSTANDING & IDENTIFYING CLEFT CONDITIONS

Normal single uvula – NO referral

Refer to Cleft Team
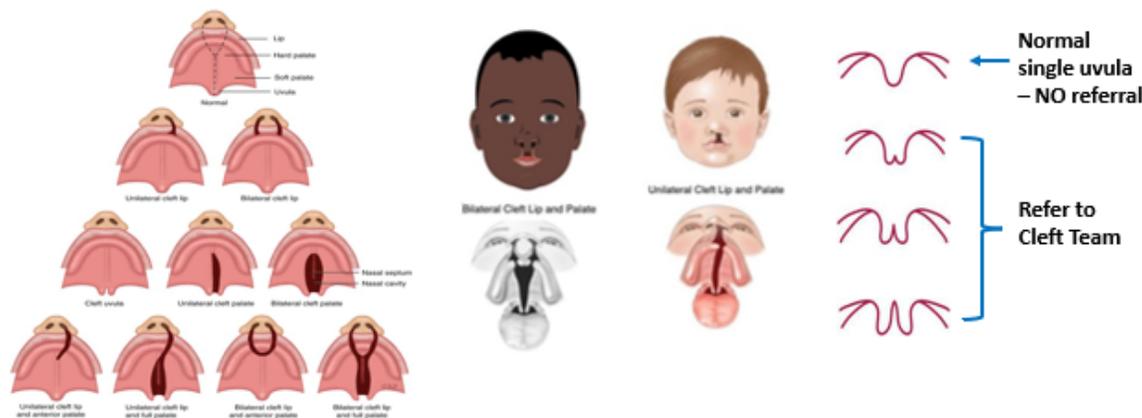
EARLY SIGNS TO IDENTIFY CLEFT PALATE:

- Not maintaining suction/ latch
- Rapid sucking, but breast/bottle still full or only minimally reduced
- Prolonged feeds
- Baby unsettled during feeds
- Clicking sound while feeding
- Milk coming down & out the nose (nasal regurgitation)
- Failure to thrive
- Parent intuition

NICE Guidelines & Learning Modules:

Palate examination: Identification of cleft palate in the newborn - best practice guide | **RCPCH**

www.rcpch.ac.uk/resources/palate-examination-identification-cleft-palate-newborn-best-practice-guide

Evelina London

CLEFT SERVICE REFERRAL LINE   07548 152738

J Matthews, CNS 05/2023

Evelina London | | **KING'S HEALTH PARTNERS**   **Guy's and St Thomas' NHS** NHS Foundation Trust

Treatment approach for positive speech outcomes

The ask

- **Trent's surgical approach to primary palate surgery, covering preoperative optimisation, perioperative management, timing and technique**

- **Trent's approach to speech therapy and reflections/explanations for differences in speech articulation outcomes between Trent and centres with comparable palatal function.**

The delivery

Pre/peri-operative optimisation

Surgery

Supporting speech

Pre/peri-operative care

Diagnosis visit - CNS

Home care - CNS

New Baby clinic – CNS, Paediatrician, Surgeon

Pre-admission clinic – CNS, Anaesthetist, Surgeon

Home care - CNS

Surgery

1 week Postoperative visit - CNS

3 months postoperative review – SLT, Surgeon

Monthly MDT patient review

Nottingham Children's Hospital

We are here for you

Surgery

A Technique for Cleft Palate Repair

Brian C. Sommerlad, M.B., B.S., F.R.C.S.

London and Essex, United Kingdom

The author has developed a technique of palate repair that combines minimal hard palate dissection with radical retropositioning of the velar musculature and tensor tenotomy. The repair is performed under the operating microscope. Results are reported for 442 primary palate repairs performed between 1978 and 1992 inclusive, with follow-up of at least 10 years. In 80 percent of these palate repairs, repair was carried out through incisions at the margins of the cleft and without any mucoperiosteal flap elevation or lateral incisions. Secondary velopharyngeal rates have decreased from 10.2 to 4.9 to 4.6 percent in successive 5-year periods within this 15-year period. Evidence from independent assessment of speech results in palate re-repair and submucous cleft palate repair suggests that this more radical muscle dissection improves velar function. (*Plast. Reconstr. Surg.* 112: 1542, 2003.)

The abnormal musculature of the cleft palate was described by Fergusson[1] and then by Veau,[2,3] who described the abnormal tensor veli palatini (the tensor) and the "cleft muscle." The first description of correction of this abnormal musculature during palate repair was by Braithwaite,[4] while Kriens[5] coined the term "intravelar veloplasty." The detailed anatomy of the muscles in the normal velum was described by Boorman and Sommerlad,[6] who demonstrated that the levator veli palatini muscle (the levator) occupied the middle 40 percent of the velum.

Interest in the tensor was related to techniques to release its tension to facilitate palate closure. Liston[7] in London described tensor tenotomy, and Billroth[8] in Vienna described fracture of the hamulus, both designed to make closure of the palate easier. Anatomical dissections of the normal tensor tendon have shown that it is at least partially attached to the hamulus and that division of the tensor tendon medial to the hamulus should not affect the role of the muscle in eustachian function. The tensor tendon normally fans out to form the relatively elastic aponeurosis, which occupies the anterior third of the velum. In the cleft, the tensor tendon is in two parts. Its most nasal component forms a dense fibrous triangular structure, close to the nasal mucosa, passing from the hamulus and attached to the posterior border of the hard palate laterally. A more oral component passes toward the oral mucosa immediately behind the greater palatine neurovascular bundle and is well seen when lateral releasing incisions are made.

The normal levator is not significantly attached to the tensor aponeurosis, but it reaches the midline in the middle 40 percent of the velum. The levator muscle in the cleft is, however, closely related to the tensor tendon–like aponeurosis and is inserted mainly at the margins of the cleft in the anterior half to two thirds of the velum.

Cutting et al.[9] have independently evolved a technique of radical reconstruction of the palatal musculature, which has much in common with the technique to be described but some differences. In particular, the author's technique does not require mucoperiosteal palatal flap elevation, the velar musculature is exposed by raising the oral mucosa in a plane between the mucous glands and the muscles, the nasal layer is closed before muscle retropositioning, mucous glands are left attached to the nasal mucosa near the midline, and both the oral and the nasal components of the tensor tendon are divided from their insertions. The operation is carried out under the operating microscope and with knife rather than scissor

Plastic and Reconstructive Surgery

Early proactive SLT support

Speech and Language Therapy: How you can help your child in the early years

Information for parents and carers

Trent Regional Cleft Lip & Palate Service

This document can be provided in different languages and formats. For more information please contact:

Speech and Language Therapy
Trent Regional Cleft Lip & Palate Service
Tel: 0115 9691169 ext 59442

BABBLE BAG

A specially selected bag of toys for parents to use with a child who has had a cleft palate to encourage early sounds, words and language

Speech and Language Therapy Service,

Trent Regional Cleft Network.

Kindly funded by the Nottingham Hospitals Charity

Broadening the therapeutic environment

Variety of SLT

REDACTED IMAGES

SLT review pathway

3 months postoperative review – SSLT, Surgeon

Babble advice session – Link SLT

18-24/12 speech assessment - SSLT

3-year-old speech assessment - SSLT

5-year-old Audit MDT – SSLT, Surgeon, others

Speech MDT – SSLTs, Surgeons

Therapy – SSLT, Link SLT

Surgery - surgeon

Therapy – SSLT, Link SLT

Nottingham Children's Hospital

We are here for you

Summary

Ensuring "thriving" babies – CNSs/Paediatricians

Accurately delivered reliable surgical technique to optimise healing and outcomes – Surgeons/Anaesthetists/Nurses

Encourage a speech rich environment, close monitoring, and timely support – Parents/SLTs/others/Surgeons

Secondary surgery for positive speech outcomes

Approach to secondary speech surgery

Dave Drake

Consultant Cleft and Maxillofacial Surgeon

Royal Hospital for Children, Glasgow

Previously

Morriston Hospital, Swansea

(2005 to 2018)

Helen Extence

Lead Speech and Language Therapist

Morriston Hospital , Swasnea

Why have I been asked to speak

20% of children in South Wales had secondary speech surgery.

Of these, 82% had no evidence of a structurally-related issue after surgery (national average: 58%, cleft service range: 23%-82%)

Not just about speech surgery but how a Cleft MDT of surgeon and speech therapists achieve good results

Helen Extence and the speech therapy team in South Wales

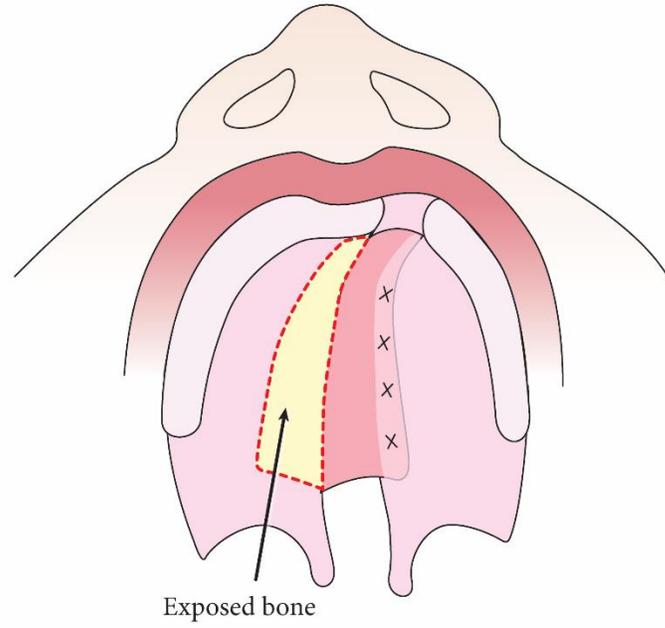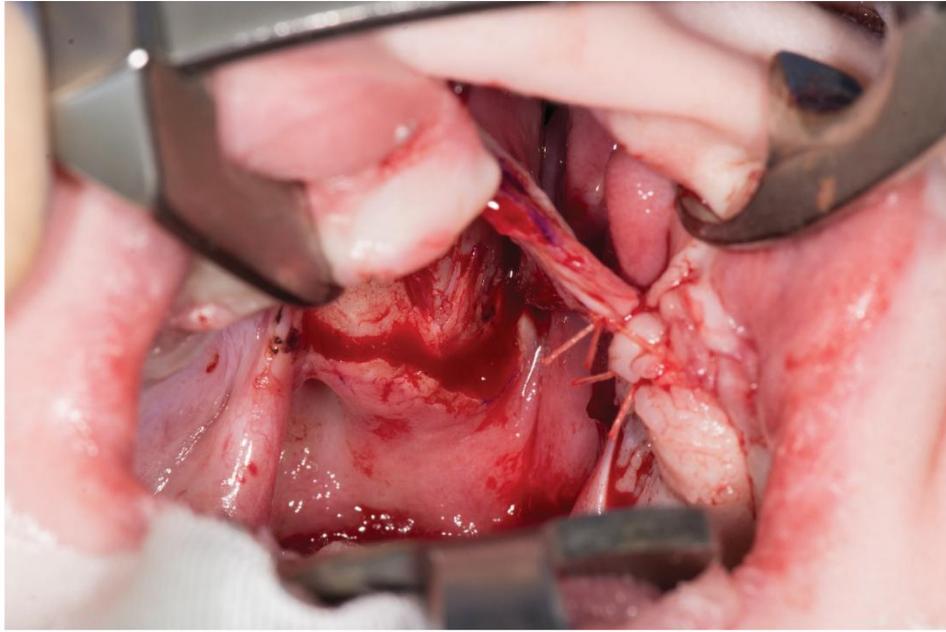(and the rest of the cleft team)

Palate Repair- my approach

Ideally at 6 months Before 1 year

Functional reconstruction of muscles

Maintain palate length

Minimise fistulas

If UCLP/BCLP then should have anterior hard palate repaired with a vomer flap at time of lip surgery if possible

Exposed bone

Palate Repair –my approach

Aims

Robust 2 layer closure hard palate and 3 layer closure soft palate
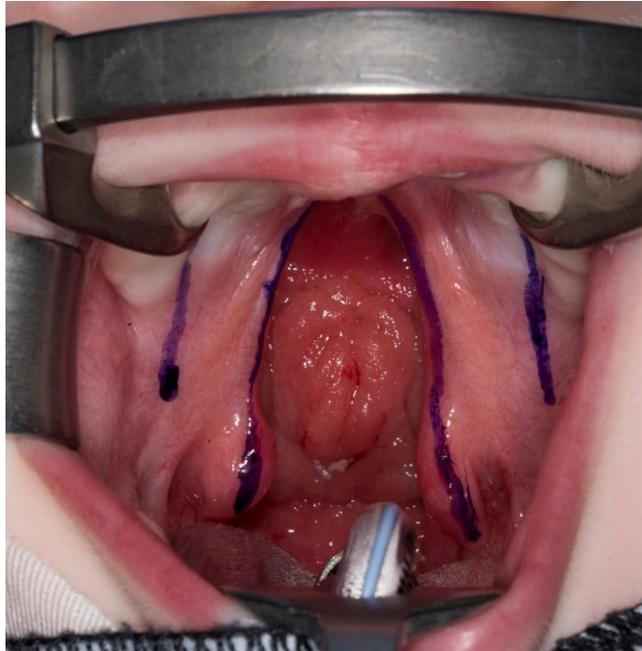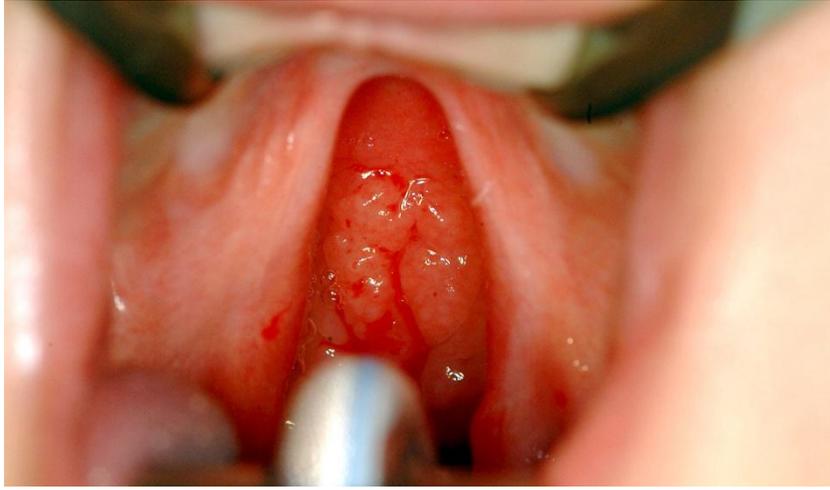
One surgery not staged

Palate Repair

Intravelar veloplasty

Sommerlad type repair

Modified Von Langenbeck approach

Keep lateral releases to a minimum

Post surgery speech review

Close well managed speech review at 18 months and 3 years

High risk patients (BCLP and wide palates) additional review at 2

Aim to reduce delays and quick decision making

Evidence of significant VPD at 18 months 2 or 3 then for review and treatment

If structural problems palate (20%) determined clinically and /or radiographically
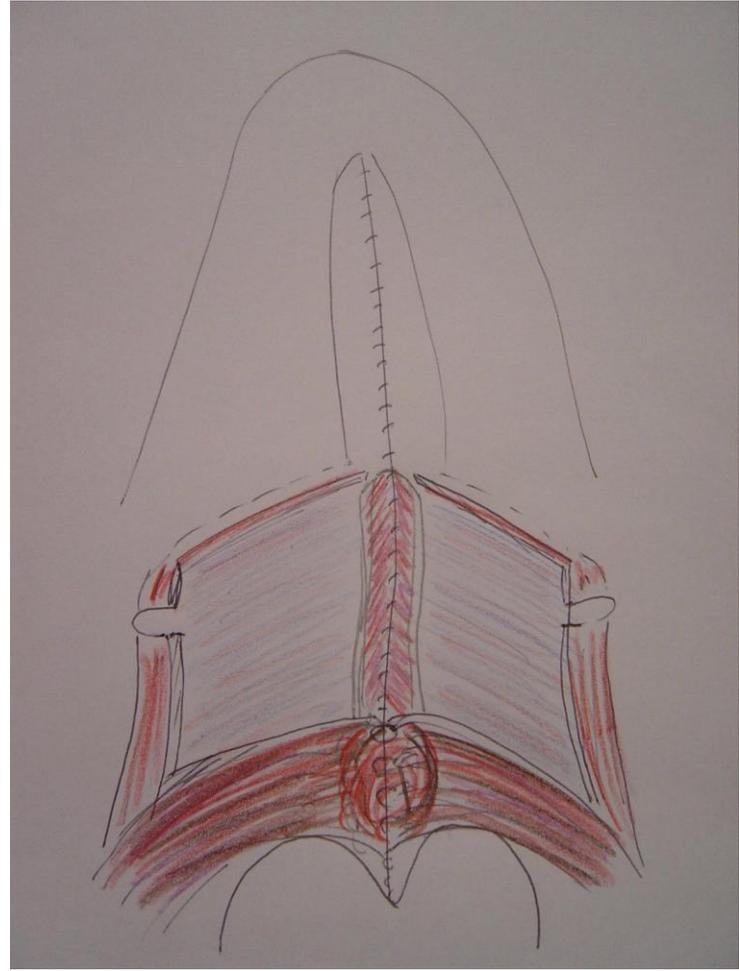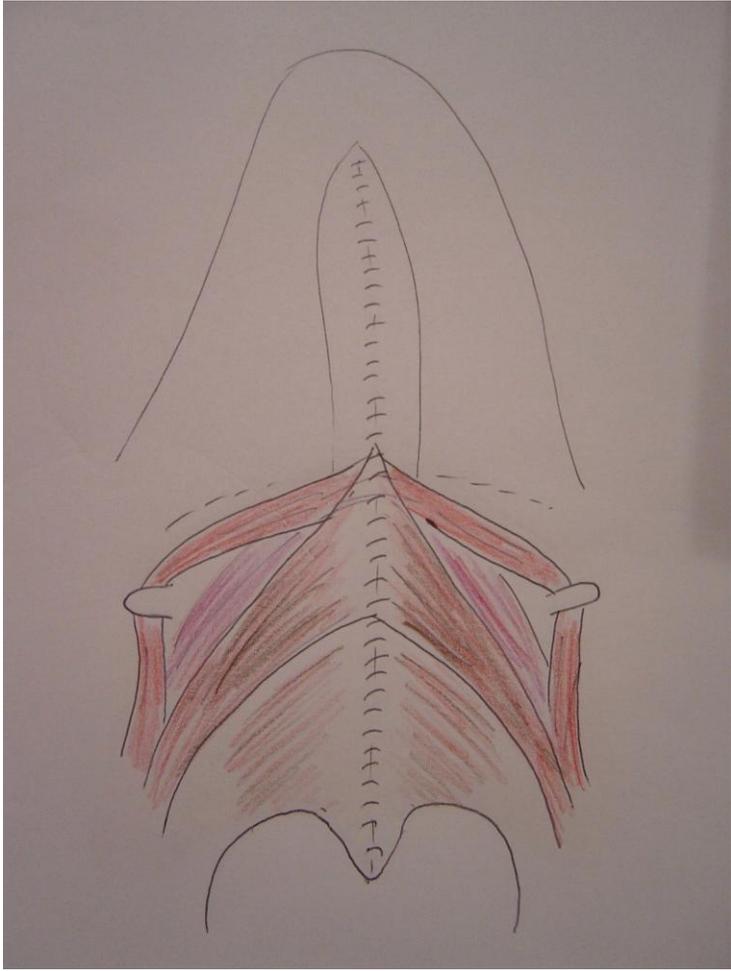
Short palate

Anterior muscle lift

Palate rerepair treatment of choice

Repeat muscle dissection and lengthen palate with posterior pillar extensions
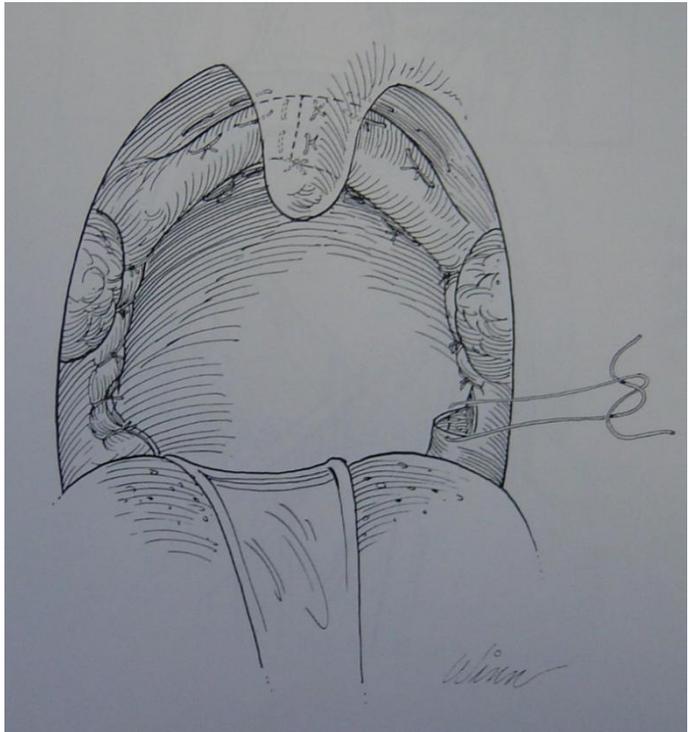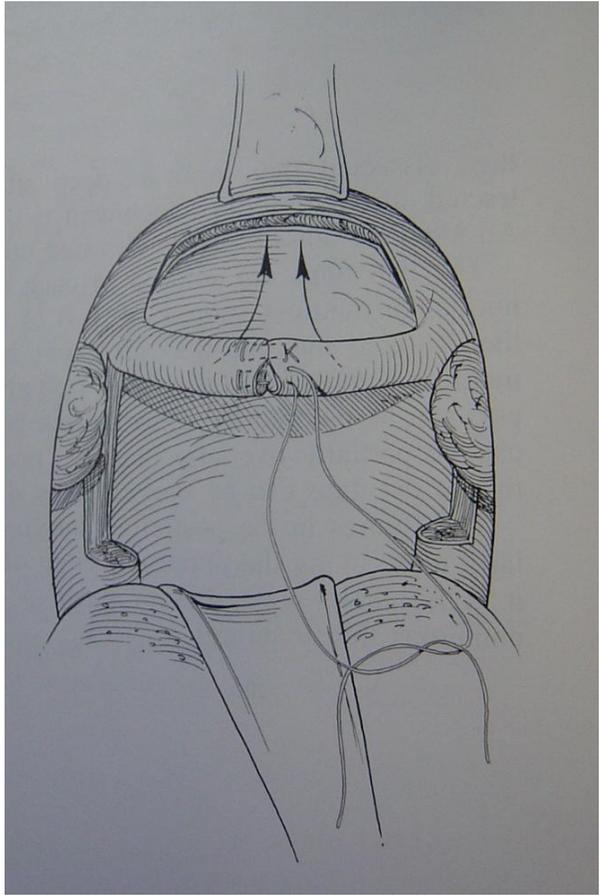
Review of 60 consecutive cases

80% successful

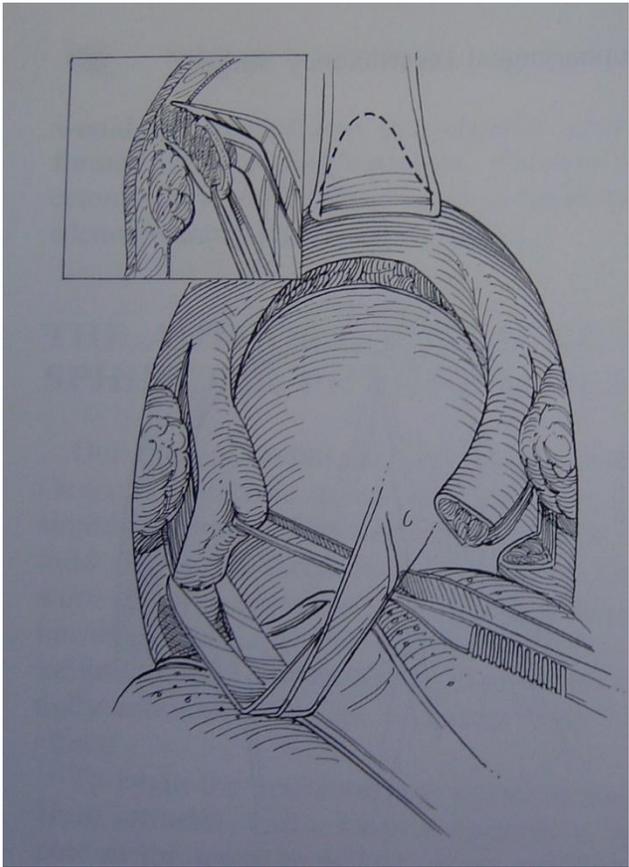# If palate rerepair not indicated or it hasn't been successful

Orticochea pharyngoplasty Jackson modification

Most patients dont need this - only 4%

Those that do 95 % successful

Summary points

Good primary functional surgery with minimal scarring

Efficient diagnostic speech therapy

Quick decision making and good use of simple rerepair technique

Above highly effective in vast majority of cases

Crane Making it Better
Approach to secondary speech surgery

Victoria Beale

Consultant Oral and Maxillofacial Surgeon

Melanie Bowden

Lead Speech and Language Therapist

17% of children in Manchester had secondary speech surgery.

Of these, 82% had no evidence of a structurally-related issue after surgery (national average: 58%, cleft service range: 23%-82%)

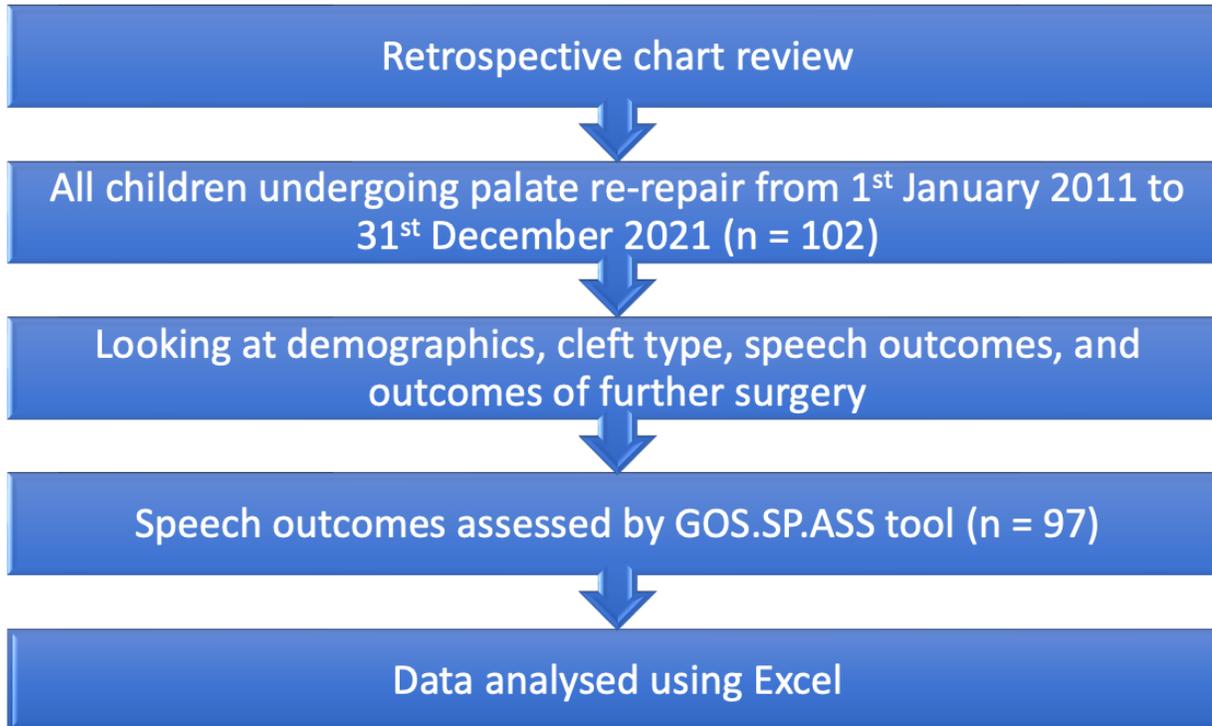# An Evaluation of Postoperative Outcomes Following Cleft Palate Re-Repair for Velopharyngeal Insufficiency

Mairéad Kelly[1], Melanie Bowden[2], Victoria Beale[2]

[1]University of Manchester, Manchester, United Kingdom, [2]Royal Manchester Children's Hospital, Manchester, United Kingdom

NHS Manchester University NHS Foundation Trust

MANCHESTER 1824 The University of Manchester

Methods

Retrospective chart review

↓

All children undergoing palate re-repair from 1st January 2011 to 31st December 2021 (n = 102)

↓

Looking at demographics, cleft type, speech outcomes, and outcomes of further surgery

↓

Speech outcomes assessed by GOS.SP.ASS tool (n = 97)

↓

Data analysed using Excel

Results
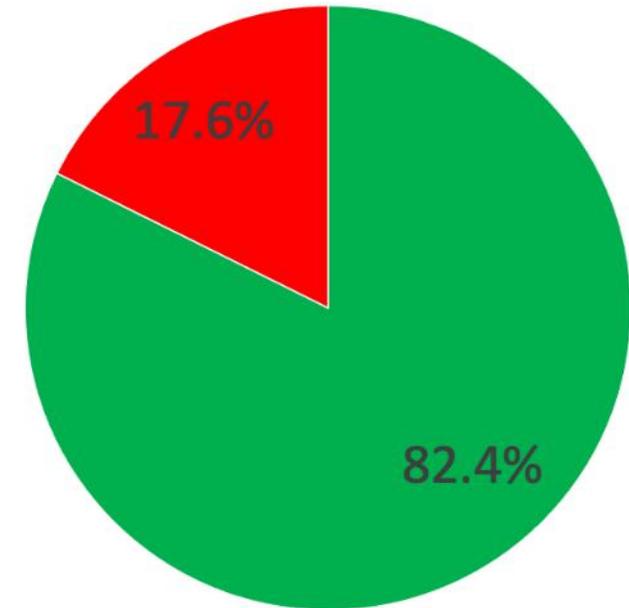
- No further surgery required ■ Required further surgery

Figure 1: Percentage of Patients Requiring Further Surgery

Manchester Approach Summary

Efficient Speech Investigation Clinic
- Speech Therapist / Radiographer / Surgeon / Dentist
- Waiting List / Consent / Post operative advise / Dental assessment

Palate re-repair
- First line treatment including in palates where lift seems posterior
- Large oral layer Z plasty / lateral scar release / midline scar excision / radical muscle dissection / buccal fat across anterior soft palate

Buccal Flap palatal lengthening
- Second line if ongoing VPI after palate re-repair

Pharyngoplasty
- Third line, rarely needed for cleft patients

Speech therapy for positive speech outcomes

Explanations for achieving good articulation outcomes
Sharing approach to therapy

- early intervention

- clear criteria for intervention at AH

- correspondence with local SLTs and use of digital health platforms

- regular community liaison clinics

- training packages and annual training day for community SLTs

- time, negotiation and transparency

- looking forward – Speech Path App, more detailed correspondence re outcomes

Q&A

Database developments

New CRANE information leaflets & consent forms

Has your child been born with a cleft lip and/or palate in England or Wales?

What is the CRANE Database?

The **C**left **R**egistry and **A**udit **NE**twork (CRANE) is a national database that collects information about children born with cleft lip and/or palate across the UK. **Information gathered by CRANE has helped improve the care and treatment of children and families affected by a cleft.**

Why is information collected?

Improve care and treatment by highlighting and sharing best practice.

Reports are produced that let each cleft service know where they are doing well and where they can improve.

Check whether cleft care meets national standards and is consistent for every child, everywhere.

Count the number of babies born with a cleft each year.

How is the information used?

☑ Data is analysed and summarised in reports for both cleft teams and cleft service users

☑ Names or details that could identify a child are never shared publicly

☑ Quality improvement activities are run to highlight and share learnings of best practice

What information do we collect and use?

CRANE collects some identifiable registry information on children born with a cleft in England and Wales[1] without consent. This is done under 'Section 251 support' from the Secretary of State for Health and Social Care, on advice from the Confidentiality Advisory Group (CAG). CAG is an independent group that checks patient data is used lawfully and ethically.

Without consent, CRANE collects:

- NHS number*
- Patient number used in cleft centre
- Year of birth
- Year deceased (if applicable)
- Sex
- Ethnic group

- Gestational age and birthweight
- Time of cleft diagnosis
- Type of cleft condition and other diagnoses
- Name of hospital/organisation making cleft referral
- Time of first contact with cleft team

* This is a key identifier that prevents duplication and reduces the risk of missed records. It also allows us to differentiate between records and check for accuracy against clinical data.

It is only **with consent** that CRANE can collect information on cleft-related treatments and measures of progress. Measures of progress cover growth, dental health, facial growth, speech, psychological health and wellbeing, ear, nose and throat (ENT) and hearing. This information is essential for CRANE to assess the standard of care provided to individuals born with a cleft.

Our full data dictionary shows all data items we collect and is available at www.crane-database.org.uk

[1] Information is collected under a different legal basis in Northern Ireland and Scotland.

Updated January 2026

The CRANE Database is a registry and clinical audit. It is not research, so no extra appointments or assessments are needed.

With **additional consent for data linkage**, CRANE can link at an individual level to other official national datasets:

Source	Examples of what we learn
Health records (Hospital and screening data)	Number of hospital visits, length of stay, additional diagnoses and treatments. Early hearing status and likelihood of temporary hearing loss or permanent hearing loss by cleft characteristics
Educational/school records	Attainment levels, school absence, support provision

Examples of care improvements resulting from CRANE

CRANE found that more than 1 in 4 babies with a cleft palate had their condition missed at birth. A best-practice guide now helps healthcare professionals check the newborn palate more carefully, so that they are diagnosed as early as possible.

Using linked data, CRANE found that children born with a cleft were, historically, more likely to miss school and didn't do as well as peers at age 7. This led some cleft services to change how they schedule outpatient appointments to better support children's education.

Keeping your information safe

The CRANE Database conforms to the confidentiality rules established by the UK GDPR, the UK Data Protection Act 2018, the NHS Act 2006, and the Health and Social Care Act 2012. All personal information is handled securely and in line with legal and contractual obligations.

CRANE reports show grouped, anonymised data. We do not use any information in our reports that could be used to identify you or your child. You can see copies of our reports by visiting www.crane-database.org.uk/reports-home/.

Access to records is strictly limited to approved cleft care professionals and authorised CRANE staff, all bound by confidentiality agreements. More information on privacy can be found here.

Your choice

You can opt out of your identifiable data being shared with CRANE at any time. To opt out, contact your cleft team or CRANE at crane@rcseng.ac.uk
If you have applied for National Data Opt-Out (NDOO), you can still be included in CRANE by giving consent. Your consent will override an NDOO.

What next?

- Your Clinical Nurse Specialist can answer any questions you have.
- You will be given a CRANE consent form to read and indicate your consent wishes.

We are committed to helping healthcare professionals provide the best evidence-based care for people with cleft lip and/or palate. This is only possible because thousands of families have consented for CRANE to collect information about their child's cleft and related care. **We are very grateful to every family agreeing to share information. This helps to improve care for all children born with a cleft in the UK.**

Updated January 2026

CRANE information for families

Gestational age and birthweight

- Now open to all registrations, not just consented cases.
    - CAG approval covering England and Wales. NI to follow too.

- Submit data for all cases born in 2026 onwards
    - We are requesting an amendment to apply this change retrospectively

- Adding '**+ days**' to gestational age. Currently just whole weeks.

- Moving to '**Patient details**' tab from 'Outcomes' tab

- We can verify our early findings that babies with cleft are more likely to be:
    - born premature
   - Born with low birthweight

5-year-old index

- Now open to complete BCLP cases (LAHSAL)
- Data can be entered retrospectively and in bulk using imports
- Dr Susana Dominguez-Gonzales (Liverpool) has scores for cases going back to 2005.
- CRANE will support entry of retrospective cases.
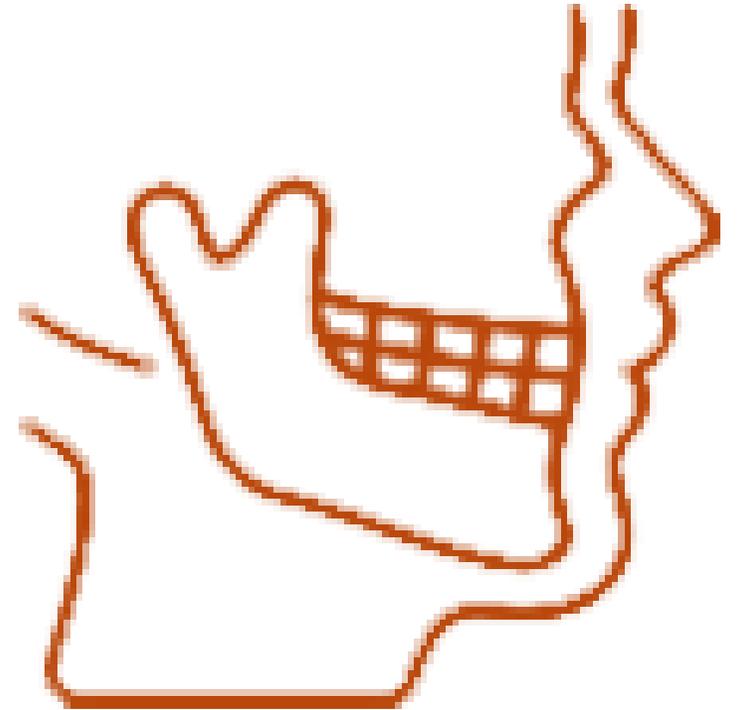
Cleft Q & TIM at 10y (psychology outcome)

- CRANE working with Psychology CEN
- There will be separate Cleft Q & TIM tabs under 10-year outcomes section on database.
- Psychological and Social Functioning sub-scales to be submitted
  - 10 questions each subscale (each rated 1'never' to 4 'always')
- Cleft Q data fields should be open by May 2026
- Data can be entered retrospectively and in bulk (imports)
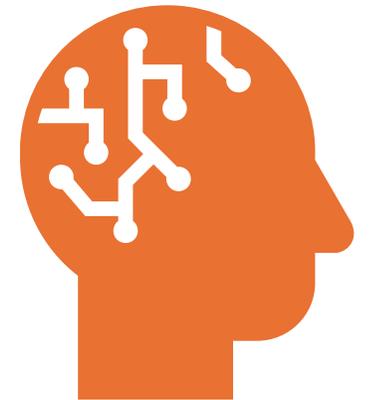
Surgical timings – under consideration

- **Lip**
  - Date of 1st primary lip adhesion/repair
  - Date definitive lip repair

- **Palate**
  - Date of 1st primary palate repair
  - Date primary palate repair complete

- **Speech surgery**
  - Date of 1st surgery for speech purposes
  - Date of 2nd surgery for speech purposes

Royal College
of Surgeons
of England
ADVANCING SURGICAL CARE

CRANE
RCS
CLEFT REGISTRY & AUDIT NETwork

Key dates

- Q& A webinar: **Monday 23 February 2026**, 10:30-12:00

- Dashboard Q3 25/26: **Friday 13 March 2026**

- CD/CL webinar: **Wednesday 20 May 2026**, 10:30-12.00

- Annual Report Extract taken: **Sunday 28 June 2026**

- Dashboard Q4 24/25: **Friday 19 June 2025**

- Outlier policy letters sent to Clinical Directors: **August 2026**

Thank you