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: Responses to outlier process

Results of the audit in England, Wales, Northern Ireland and Scotland for children born with a cleft between January 2016 and December 2018

On behalf of the Cleft Development Group

Responses to outlier process

Cleft Services were notified of their outlier / alert status on 15 August 2025, in accordance with the Outlier Policy[1], piloted and introduced between 2022 and 2024, and formally implemented from 2025 onwards.

Indicators subject to the Outlier Policy currently pertain to the five-year-old cohort only (2016-2018 births) and include consent verification, and data completion and outcomes for five-year outcomes covering child growth, oral health, facial growth, speech and psychology.

Alert and outlier identification

- For negative or positive outlier status, the data point must be beyond three standards deviations from the national mean (outside the outer control limits of the funnel, see **Appendix 1**).
- For negative or positive alert status, the data point must be between two and three standards deviations from the national mean (between the inner and outer control limits of the funnel, see **Appendix 1**).
- Where a Cleft Service has been an alert for two or more consecutive reporting periods (in 2024 and 2025), the service is considered an outlier.

Key			
++*	Positive outlier for ≥2 consecutive reporting periods	- -*	Negative outlier for ≥2 consecutive reporting periods
++	Positive outlier	- -	Negative outlier
+*	Positive alert for ≥2 consecutive reporting periods - considered positive outlier	-*	Negative alert for ≥2 consecutive reporting periods - considered negative outlier
+	Positive alert	-	Negative alert
	Within 2 standard deviations of the national average	NP	Not plotted due to insufficient number of cases (<10)

Cleft Services identified as **outliers / alerts** were asked to provide a written response to CRANE, confirming:

- confidence in the data,
- willingness (or not) to receive external review, and
- reasons for the outlier status, including information on an initial review of local practice and potential learning points that could be shared.

Responses to indicators with **alert** status were welcome but not mandated. All responses provided during the 2025 outlier process are presented in this document.

Documents related to this product, for reference, published separately:

Document	**Published**
CRANE 2025 Annual Report	December 2025
CRANE 2025 Annual Report: Supplementary tables (Appendices) (Excel Workbook)	December 2025
CRANE Outlier Policy[2]	August 2025 (updated)

[1] https://www.crane-database.org.uk/resources/crane-outlier-policy/

1. Newcastle cleft service

Notification of status

Data items	Newcastle			
	Status	Cleft Service (%)	National Average (%)	Revised National Average (%)[1]
Consent verification	++*	98.7%	92.5%	-
Data completeness				
Child growth	++*	77.0%	51.2%	58.3%
Dental health (dmft)[2]	++*	85.1%	55.7%	58.0%
Facial growth	+*	84.0%	55.5%	61.4%
Speech	+*	83.7%	69.5%	72.0%
Psychology (TIM)	++*	90.5%	72.3%	73.9%
Clinical outcomes				
Child growth (healthy BMI)		84.2%	83.5%	82.8%
Dental health (dmft > 0)[3]		40.3%	38.6%	42.1%
Dental health (dmft > 5)[3]		14.2%	15.6%	16.9%
Facial Growth (Good scores)		66.7%	53.9%	53.9%
Speech (Standard 1)[4]		60.5%	53.7%	54.4%
Speech (Standard 2a)[4]	+*	85.2%	73.5%	73.7%
Speech (Standard 3)[4]		63.8%	62.0%	63.6%
Psychology (TIM 1a+)	++*	99.3%	91.6%	90.9%

Response

Thank you very much for your letter dated 15 August 2025 on behalf of the CRANE database team following the analysis of the CRANE 2025 Annual Report.

I note we are a positive outlier for a number of data items.

I can confirm:

- We are confident in the data

- We would be willing to receive an external review, and

- Our reasons for outlier status maybe attributable to:

- Well-funded and usually well-resourced cleft MDT (including a dedicated data coordinator and cleft co-ordinator)
- A stable MDT team
- A well organised and managed clinical workload aiming to adhere to treatment protocols (e.g. Triage clinics to ensure patients on correct pathways, regular review of operating and waiting lists).
- Entire cleft MDT recognises the value of CRANE, the audit process and continual improvement. Time built into job plans to facilitate this.

Mr David Sainsbury

Clinical Lead
Newcastle Cleft Service

2. Leeds cleft service

Notification of status

Data items	Leeds			
	Status	Cleft Service (%)	National Average (%)	Revised National Average (%)[1]
Consent verification	++*	99.5%	92.5%	-
Data completeness				
Child growth	++	75.1%	51.2%	58.3%
Dental health (dmft)[2]	++	72.9%	55.7%	58.0%
Facial growth		57.1%	55.5%	61.4%
Speech		73.1%	69.5%	72.0%
Psychology (TIM)		74.6%	72.3%	73.9%
Clinical outcomes				
Child growth (healthy BMI)		89.0%	83.5%	82.8%
Dental health (dmft > 0)[3]		40.4%	38.6%	42.1%
Dental health (dmft > 5)[3]		14.8%	15.6%	16.9%
Facial Growth (Good scores)		37.5%	53.9%	53.9%
Speech (Standard 1)[4]	-	42.2%	53.7%	54.4%
Speech (Standard 2a)[4]	-*	61.4%	73.5%	73.7%
Speech (Standard 3)[4]	-	49.8%	62.0%	63.6%
Psychology (TIM 1a+)	++*	99.3%	91.6%	90.9%

Response

Response to CRANE Outlier Letter 2025

This response has been submitted on behalf of the Regional Cleft Lip and Palate Service hosted by Leeds Children's Hospital.

We remain committed in our region to achieving the best clinical outcomes and experiences for our patients and their families. There are many areas of strength in our audit practice and patient outcomes, which we are proud of. We also recognise there are areas for improvement to ensure we are supporting our patients to achieve their optimum outcomes across all aspects of their care. We are working hard as a team to address these.

Data Completeness

1. **Consent verification** – positive outlier for two consecutive reporting periods

The consent data within this report relates to a time when our service used paper notes, which our clinical nurse specialists had at patient appointments. Consent documentation was included in pre-prepared, readymade packs, which prompted our nurses to discuss and collect consent. Any missed consents were followed up by our audit co-ordinator.

2. **Child growth** – positive outlier

We believe this relates to the structure and efficient organisation of our multidisciplinary audit clinics, both in advance and on the day of clinic. These ensure children are seen at the appropriate time, and one of our clinical nurse specialists is present in all clinics to undertake weight and height measurements. This reflects a commitment to obtain records from as many patients as possible.

3. **Dental health (dmft)[2]** – positive outlier

We are confident the report gives an accurate representation of the dental health data we submitted for our patients born in 2016-18. We believe the main reason for our positive outlier status is that our paediatric dentistry team prioritises their attendance at our 5-year audit clinics, both centrally and in spoke clinics. The team actively follows-up any children who are not brought to these multidisciplinary clinics, and separate appointments are offered if necessary.

Clinical Outcomes

1. **Speech (Standard 2a)** – negative alert for two consecutive reporting periods (considered negative outlier) and **Speech (Standards 1 and 3)** – negative alert

Our team is disappointed with these findings of the report. However, they were not completely unexpected given the overlap of patient cohorts in consecutive reports.

We have a good level of confidence in the data, although there are some discrepancies that we need to examine. We appreciate the inclusion of risk adjustment as this allows for fairer comparisons of speech outcomes between cleft centres and strengthens confidence in the findings. We have identified some discrepancies with the inclusion of some patients with additional diagnoses, including syndromes. We will seek further clarification around this and ensure any inaccuracies are addressed for future reporting.

We have reviewed the CAPS-A speech outcomes for every child born 2016-18 who did not have a green profile. In 91% of cases, the audit outcome aligned with the speech features that had been reported clinically, supporting our confidence in the data. There is a small cohort of patients who missed out on a green profile by a marginal degree. We are confident that we have adhered to CAPS-A guidelines when categorising speech features and measuring these against the national standards. However, we will continue to raise queries in appropriate national forums to ensure this continues and to support consistent implementation nationally.

We are reviewing the clinical records of patients whose speech outcomes did not meet national standards, with the aim of identifying factors that may have contributed. This investigation is on-going and will conclude with an action plan in due course. One area for improvement we have already identified (relating to standards 1 and 3) is the time it takes to resolve speech difficulties. We have already taken steps to address this. For example, shortened the pathway from speech assessment to a decision about surgical treatment, and reconfigured our specialist therapy pathway and interaction with local services.

For some children whose speech outcomes did not meet national standards, treatment was not required. Information from parents/carers about their child's functional speech intelligibility (i.e., how well their child is understood by different people), the impact of any speech differences, and their wishes for their child, is a key component of our speech assessments. This will remain at the forefront of our discussions with families about potential treatment.

2. **Psychology (TIM 1a+)** – positive outlier for two consecutive reporting periods

This reflects consistent presence of clinical psychology at all our multidisciplinary cleft clinics to screen and provide input where necessary.

As a team, we appreciate the opportunity to provide this response, and welcome further queries or discussion. We will support and engage with an external review of our service if this is recommended. Whilst we have positive outlier status to be proud of in several areas, we acknowledge our negative status in relation to speech outcomes. We remain committed to refining aspects of our service provision that will continually improve outcomes for our patients.

Written by:

Dr Samantha Calladine (Acting Lead Clinician and Lead Specialist Speech and Language Therapist) in collaboration with the team.

Leeds Cleft Service

3. Liverpool cleft service

Notification of outlier status

Data items	Liverpool			
	Status	Cleft Service (%)	National Average (%)	Revised National Average (%)[1]
Consent verification	+	96.7%	92.5%	-
Data completeness				
Child growth	++	71.6%	51.2%	58.3%
Dental health (dmft)[2]	++	75.1%	55.7%	58.0%
Facial growth		51.2%	55.5%	61.4%
Speech		71.8%	69.5%	72.0%
Psychology (TIM)	++*	85.8%	72.3%	73.9%
Clinical outcomes				
Child growth (healthy BMI)		84.4%	83.5%	82.8%
Dental health (dmft > 0)[3]		46.3%	38.6%	42.1%
Dental health (dmft > 5)[3]		17.4%	15.6%	16.9%
Facial Growth (Good scores)		50.0%	53.9%	53.9%
Speech (Standard 1)[4]		56.7%	53.7%	54.4%
Speech (Standard 2a)[4]	-	63.9%	73.5%	73.7%
Speech (Standard 3)[4]		71.6%	62.0%	63.6%
Psychology (TIM 1a+)	-	85.8%	91.6%	90.9%

Response

Response to CRANE regarding outlier status within CRANE 2025 Annual Report including 2016-2018 births (Liverpool)

Thank you for highlighting the **positive outlier** status for:

Consent verification- Positive alert

Child Growth- Positive outlier

Dental Health (dmft)- Positive outlier

Psychology (TIM)- Positive outlier for 2 consecutive reporting periods

I believe this is due to a well organised process that has been put into place by our Cleft Nursing, Paediatric Dental and Psychology teams. Our cleft coordinators work in conjunction with the clinical teams to try to ensure that the dataset is as complete as possible.

We made a decision some years ago to hold all 5 year old audit clinics at Alder Hey Children's Hospital in Liverpool. Many outreach clinics are held across our geographical footprint including: Ysbyty Gwynedd/Bangor Hospital, Ysbyty Glan Glwyd/Glan Clwyd Hospital and Wrexham Maelor Hospital in North Wales. Outreach clinics are also held at Royal Preston Hospital, Lancashire. We felt that by holding all the audit clinics at Alder Hey we would be able to provide the best standard of data collection possible with the resources available to us. We recognised that this would mean additional travel for our families for one clinic visit, but we felt robust data collection would benefit all involved in Liverpool cleft care, including our patients and families.

Thank you for highlighting the **negative alert** both speech (standard 2a) and psychology (TIM1a+).

Speech (standard 2a)

This outlier status was not anticipated. We have been through a period where the non-clinical member of staff responsible for inputting this data had been absent from the trust. On initial inspection of the CRANE data, there did appear to be a significant number of inaccurate speech data entries.

A piece of work has been carried out to validate the data entered. There are Inaccuracies in the number of children meeting speech standard 2a. These are due to errors in data entry. Five patients were identified as inaccurately having had secondary speech surgery.

Nasal airflow data was incorrectly entered for two patients.

For one case the live assessment differed significantly with the CAPS-A consensus. A local process will be developed to further understand the reasons why the standard has not been met for such cases.

Psychology (TIM1a+)

As acknowledged previously in the Crane 2024 annual report outlier responses, "We would like to acknowledge a positive trend in data over the reporting period, however, due to the nature of the 3 year reporting period, we project that despite making recent improvements to our service we will likely remain outliers for the next reporting period."

We have identified the following factors that have unfortunately continued to negatively impact on our ability to review 5 year olds face to face for audit, and therefore on provision of TIM 1a+ activity and data:

- Changes to usual MDT clinics during/following COVID-19 pandemic (e.g. 5 year olds not being invited to clinics, 5 year olds being seen out with dedicated audit clinics, and in virtual rather than face to face clinics
- Lack of Clinical Psychology resources (i.e. due to annual leave, long term and acute sickness, and lack of maternity leave cover)

• We continue to work hard with our MDT colleagues to improve audit processes, including identification of those eligible for audit and invitation to appropriate clinics.

• We continue to review our Cleft Clinical Psychology service and are pleased to have recently recruited to our service, and hope this will allow us to a provide a more resilient and high performing service in future.

• We are willing to welcome external review, to identify any further potential learning points.

Mr Chris Sweet

Consultant Cleft, Oral & Maxillofacial Surgeon
Clinical Director, North West, North Wales & Isle of Man Cleft Network
Liverpool Cleft Service

4. Manchester cleft service

Notification of outlier status

Data items	Manchester			
	Status	Cleft Service (%)	National Average (%)	Revised National Average (%)[1]
Consent verification		92.4%	92.5%	-
Data completeness				
Child growth	++*	87.4%	51.2%	58.3%
Dental health (dmft)[2]	++*	93.2%	55.7%	58.0%
Facial growth	+*	84.4%	55.5%	61.4%
Speech	+	81.4%	69.5%	72.0%
Psychology (TIM)	++*	84.7%	72.3%	73.9%
Clinical outcomes				
Child growth (healthy BMI)		82.5%	83.5%	82.8%
Dental health (dmft > 0)[3]		46.9%	38.6%	42.1%
Dental health (dmft > 5)[3]		19.4%	15.6%	16.9%
Facial Growth (Good scores)		51.9%	53.9%	53.9%
Speech (Standard 1)[4]		61.5%	53.7%	54.4%
Speech (Standard 2a)[4]		73.1%	73.5%	73.7%
Speech (Standard 3)[4]		71.7%	62.0%	63.6%
Psychology (TIM 1a+)	- -	82.6%	91.6%	90.9%

Response

RE: CRANE 2025 Annual Report- Outlier Identification

Feedback on outlier status

Manchester is a **positive outlier** for 2 consecutive reporting periods for data completeness in recording of child growth, dental health (dmft) and psychology (TIM); a positive alert for 2 consecutive periods for data completeness in facial growth and a positive alert for data completeness in speech.

The positive outlier statuses are testament to the trojan efforts of our cleft coordinator, supported by our experienced dental therapist and reception team, to ensure audit clinics (where most of this data is gathered) are optimally booked, patients are contacted and chased up if they miss their appointments. The extended MDT are engaged in audit clinics with the team working collaboratively, ensuring no stone is left unturned in efforts to achieve data completeness.

We're flagged as a **negative outlier** for clinical outcomes in psychology (TIM 1a+).

The psychology team have investigated this further with their findings detailed below:

Background The CRANE 5-year audit (2021–2023) reports 28 patients with a TIM score of 0 (psychologist not present) at Manchester Cleft Service. To understand this outlier, patient-level data was extracted from CRANE, yielding 24 records, of which only 13 included identifiable clinic dates.

Findings: Potentially inappropriate TIM scores: 11 patients may have an inaccurate TIM score of 0. Four of these were confirmed and corrected using ACCESS clinic records (all from 11/10/2023).

The remaining seven could not be verified due to missing clinic notes.

Appropriate TIM scores of 0: The remaining scores can be explained by staff sickness, annual leave, or staffing gaps on the respective clinic dates.

Dates with potential corrections:

12/01/2022 – 3 inappropriate 0 scores

06/07/2022 – 2 inappropriate 0 scores

10/08/2022 – 2 inappropriate 0 scores

11/10/2023 – 4 inappropriate 0 scores (corrected)

Conclusion: Most TIM scores of 0 are justified due to the absence of the Assistant Psychologist. A small proportion of scores (up to 11 patients) appear incorrect/inappropriate; 4 have now been corrected. Remaining discrepancies likely reflect incomplete data in the CRANE extract.

Clinic Date	Patients Eligible	TIM of 0 Reported	Inappropriate TIM of 0	Corrected?	Notes / Reason for TIM of 0
21/07/2021	N/A	N/A	0	N/A	Staff sickness (20–27 July)
12/01/2022	10	3	3	No	Psychologist present; 6 patients scored ≥1, 1 not CRANE eligible
06/07/2022	4	2	2	No	1 reported "syndromic", 1 scored ≥1
10/08/2022	5	1	2	No	2 scored ≥1, 1 DNA
16/11/2022	N/A	N/A	0	N/A	Staff sickness (16–18 Nov)
26/04/2023	N/A	N/A	0	N/A	Annual leave
10/05/2023	N/A	N/A	0	N/A	AP on leave at ClinDoc interview
24/05/2023	N/A	N/A	0	N/A	AP on leave at ClinDoc interview
13/09/2023	N/A	N/A	0	N/A	Staffing gap
11/10/2023	4	4	4	Yes	Corrected using ACCESS records

The cleft psychology team would be happy to be externally reviewed but have identified the need to ensure audit clinics are coordinated with psychology leave.

I hope this proves a helpful snapshot of our outlier status.

Other comments

Our paediatric dental consultant did ask if we could add a comment about the actual dmft data- risk adjustment for social deprivation has brought us out of the negative outlier status for dmft>0 and dmft>5 but we continue to have the highest figures in both funnel plots which reflect the high levels of dental decay and social deprivation in our regions.

Any queries, please do not hesitate to get in touch

Kind regards

Ailbhe McMullin

Consultant Cleft Orthodontist
Clinical Lead for Manchester Cleft Service (Part of North West of England, Isle of Man & North Wales Cleft Network)
Royal Manchester Childrens' Hospital

5. Trent cleft service

Notification of outlier status

Data items	Trent			
	Status	Cleft Service (%)	National Average (%)	Revised National Average (%)[1]
Consent verification		89.7%	92.5%	-
Data completeness				
Child growth		58.5%	51.2%	58.3%
Dental health (dmft)[2]	- -	44.4%	55.7%	58.0%
Facial growth		66.7%	55.5%	61.4%
Speech	++*	87.4%	69.5%	72.0%
Psychology (TIM)	- -*	32.0%	72.3%	73.9%
Clinical outcomes				
Child growth (healthy BMI)		83.7%	83.5%	82.8%
Dental health (dmft > 0)[3]	+	30.6%	38.6%	42.1%
Dental health (dmft > 5)[3]		12.8%	15.6%	16.9%
Facial Growth (Good scores)		63.6%	53.9%	53.9%
Speech (Standard 1)[4]	++*	68.6%	53.7%	54.4%
Speech (Standard 2a)[4]	++*	86.5%	73.5%	73.7%
Speech (Standard 3)[4]	+	73.7%	62.0%	63.6%
Psychology (TIM 1a+)	++	100.0%	91.6%	90.9%

Response

Re: Crane 2025 Annual Report – Outlier identification

Thank you for your letter of the 15th August 2025, and our thanks to the CRANE team, and all data capturers within cleft teams across the country for collating and presenting the 2025 Report. The opportunity to use national data to help improve cleft services across the country is unique privilege.

We are delighted that the Trent Cleft Network has been identified as a **positive outlier** in several areas:

- Data completeness for speech
- Clinical outcomes in Speech Standards 1 and 2a, and in Psychology TIM scores
- And a positive alert for Speech Standard 3 and dental outcomes

At the same time, the Network has been identified as a **negative outlier** in data completeness for dental health and psychology.

Below, we outline the background to our region, our understanding of these results, and the steps we are taking to ensure continuous improvement.

Background

The Trent Cleft region is geographically large, covering Derbyshire, Leicestershire, Lincolnshire, Nottinghamshire, and South Yorkshire. To provide care as close to patients' homes as possible, the Network operates a decentralised model.

The birth cohorts included in the 2025 report are from 2016–2018, with audit data captured between 2021–2023 and processed in 2022–2024. This means that some outcomes, such as data completeness, reflect relatively recent activity, while others—such as speech and dental outcomes—reflect care delivered several years ago.

Paediatric Dental Health

The Trent Cleft Network received:

- A **negative outlier** for the amount of DMFT data submitted
- A **positive alert** for the low proportion of patients with caries experience during the audit period

We are encouraged that DMFT data submission increased from 37% in the 2024 report to 44% in the 2025 report. This improvement was supported by a senior StR attending one of our regional clinics as part of training—though we recognise this is not a long-term solution. In urban parts of the region, data collection exceeds 70%, but in less urban areas, clinics remain without paediatric dentistry input.

We received a positive alert for a lower proportion of patients with caries experience, with treatment and care indices above 70%. This demonstrates that where paediatric dentistry input is available, children receive appropriate treatment and are not left with untreated caries. This compares very favourably with national survey data, where the care index is generally below 20% and falling. We are extremely grateful to our paediatric dentists for their hard work and the clear benefit they bring to children and families. (We do, however, remain mindful that our positive alert status should be interpreted cautiously, given the absence of data from clinics serving areas of high deprivation and reduced access to dental services.)

Like many regions, Trent is affected by the national decline in NHS dental service availability. In some areas, NHS dental care is effectively unavailable, placing additional pressure on Community Dental Services to provide specialist paediatric care. Historically, the Trent Cleft Network was not commissioned to provide children's dental services across all clinics. We are actively working with Nottingham University Hospitals NHS Trust and East Midlands specialist commissioners to address this shortfall. We aim to provide care and evaluation by accredited specialists in our decentralised model.

Expanding our paediatric dental service will depend on funding. While we are committed to this goal, any improvements will take several years to be reflected in future Annual Reports.

Psychology

The Trent Cleft Network is:

- A **negative outlier** for completeness of TIM data (for two or more consecutive periods)
- A **positive outlier** for the level of psychological involvement in reported cases

We are disappointed by the negative outlier status for TIM data. However, it is important to note this reflects limitations in data capture, not an absence of psychological care or poor patient outcomes.

Historically, the Network had no dedicated psychology service. A 2016–2018 scoping exercise suggested the need for 2.4 WTE psychologists to meet both clinical and audit requirements. Since then, we have made significant progress:

- 2019: A 0.2 WTE Consultant Clinical Psychologist leadership post was created
- 2022: Recruitment of a 0.8 WTE Band 8A Clinical Psychologist (who went on maternity leave in 2023 and was only recently replaced)
- 2024: Appointment of a 0.4 WTE Band 8B Clinical Psychologist

Despite these steps, staffing has remained well below the required 2.4 WTE, and resources have rightly prioritised therapeutic interventions over audit data collection.

We are now moving towards full staffing at our currently funded level (1.2 WTE qualified psychologists), with an additional 0.35 WTE Assistant Psychologist starting soon to focus on data collection. This will strengthen our audit reporting in the coming years, although improvements will take time to appear in national reports. We will also continue to advocate for further investment to meet the full needs of our patients.

Speech

The Network has been recognised as a **positive outlier** for:

- Completeness of speech data (for two or more consecutive periods)
- Outcomes in Speech Standards 1 and 2a
- And received a positive alert for Speech Standard 3

We extend our thanks to all Speech and Language Therapists for their commitment to guiding parents, supporting children, and collaborative data processing across service. In particular, we acknowledge Lorraine Britton, whose tireless work in cleft service development and promotion of audit at a national level was fittingly recognised with an OBE in the King's Birthday Honours List this year.

Our improved performance in speech standards is the result of over a decade of collaborative effort:

- Ensuring babies are as healthy as possible before surgery by our Nursing Team, Paediatricians, and Anaesthetists
- Consistently delivering evidence-based surgical procedures and using early surgical outcome markers to inform learning and improvement
- Introducing early speech assessment and fostering close collaboration between SLTs and surgeons, enabling earlier interventions

Thank you to all involved in this collective achievement and ongoing process.

The Trent Cleft Network remains fully committed to delivering high-quality care for all patients with cleft lip and/or palate. The dedication of every team member underpins the successes highlighted in this report, and we will continue to strive for excellence while addressing areas where improvement is needed. We look forward to working closely with commissioners and our host Trust to strengthen and expand services.

Most importantly, we wish to thank our patients and their families for their support of the CRANE audit process—for attending clinics, contributing data, and helping shape the service. Their courage, resilience, and achievements remain the greatest reward for our work.

On behalf of the Trent Cleft Network Team,

Yours Sincerely,

JONATHAN SYME-GRANT
CLINICAL DIRECTOR OF THE TRENT CLEFT NETWORK

6. West Midlands cleft service

Notification of outlier status

Data items	West Midlands			
	Status	Cleft Service (%)	National Average (%)	Revised National Average (%)[1]
Consent verification	- -	85.9%	92.5%	-
Data completeness				
Child growth	- -*	11.1%	51.2%	58.3%
Dental health (dmft)[2]	- -*	28.4%	55.7%	58.0%
Facial growth	- -*	0.0%	55.5%	61.4%
Speech	- -*	52.0%	69.5%	72.0%
Psychology (TIM)	- -*	49.0%	72.3%	73.9%
Clinical outcomes				
Child growth (healthy BMI)		82.4%	83.5%	82.8%
Dental health (dmft > 0)[3]		33.5%	38.6%	42.1%
Dental health (dmft > 5)[3]		12.0%	15.6%	16.9%
Facial Growth (Good scores)	**NP**		53.9%	53.9%
Speech (Standard 1)[4]		59.0%	53.7%	54.4%
Speech (Standard 2a)[4]		76.7%	73.5%	73.7%
Speech (Standard 3)[4]		63.0%	62.0%	63.6%
Psychology (TIM 1a+)	- -*	82.0%	91.6%	90.9%

Response

Please see our response below.

To confirm:

1. Yes we have confidence in the data that has been submitted to CRANE

2. Yes to receiving external review if deemed beneficial and appropriate

Reasons for Outlier Status:

- Lack of a dedicated data co-ordinator for nearly 5 years
- Loss of data (multiple changes in administration staff over a short period, offices relocated, hospital patient database change)
- Previous psychologist not submitting any data to CRANE (internal re-allocation)
- Outlier in data completeness for consent, growth, DMFT, speech, psychology

Next Steps:

1. Birmingham Children's Hospital has finally **approved re-advertisement for a Data Co-ordinator post**. This has taken a lot of time with many iterations to gain approval - thank you CRANE for your assistance with this.

Once we have a data coordinator in post the first priority will be improving our consent, establishing a reliable process for getting and recording consent at birth and 5 yrs and to ensure that the missing data fields (demographic and LAHSHAL codes) are all entered correctly.

2. **New cleft-experienced Psychologist recruited** (start Oct 2025). Part of new appointment job plan is to oversee and co-ordinate psychology data submission.

Please let me know if any more information is needed

Mr Khurram Khan

Consultant Cleft, Plastic & Reconstructive Surgeon

Clinical Service Lead
West Midlands Regional Cleft Service

7. Cleft.NET.East cleft service

Notification of outlier status

Data items	Cleft Net East			
	Status	Cleft Service (%)	National Average (%)	Revised National Average (%)[1]
Consent verification		90.7%	92.5%	-
Data completeness				
Child growth	++*	77.6%	51.2%	58.3%
Dental health (dmft)[2]		59.0%	55.7%	58.0%
Facial growth		48.6%	55.5%	61.4%
Speech		70.7%	69.5%	72.0%
Psychology (TIM)	+	81.4%	72.3%	73.9%
Clinical outcomes				
Child growth (healthy BMI)		82.4%	83.5%	82.8%
Dental health (dmft > 0)[3]		37.6%	38.6%	42.1%
Dental health (dmft > 5)[3]		17.3%	15.6%	16.9%
Facial Growth (Good scores)		52.9%	53.9%	53.9%
Speech (Standard 1)[4]		44.3%	53.7%	54.4%
Speech (Standard 2a)[4]		73.7%	73.5%	73.7%
Speech (Standard 3)[4]		55.7%	62.0%	63.6%
Psychology (TIM 1a+)	++*	100.0%	91.6%	90.9%

Response

Thank you for the annual report. We are very pleased to be positive outlier for multiple areas. We have had a chance to discuss as a team and our key learning for achieving these are:

1. Continuous monitoring and review of patient database for follow-up and data completeness
2. Integration of systems for accurate data collection
3. Ensuring sufficient admin time
4. One area of particular focus has been ensuring the entire MDT are aware of the importance of capturing associated conditions that modify risks such as Pierre Robin Sequence

I hope this addresses your queries and as always please do not hesitate to reach out if further information would be of value.

Yours sincerely,

Ms Kana Miyagi FRCS (Plast)

Consultant Plastic and Reconstructive surgeon
Clinical Lead
Cleft.NET.East

8. North Thames cleft service

Notification of outlier status

Data items	North Thames			
	Status	Cleft Service (%)	National Average (%)	Revised National Average (%)[1]
Consent verification	+*	95.9%	92.5%	-
Data completeness				
Child growth	- -	48.6%	51.2%	58.3%
Dental health (dmft)[2]	- -*	13.0%	55.7%	58.0%
Facial growth		63.6%	55.5%	61.4%
Speech		65.9%	69.5%	72.0%
Psychology (TIM)		73.4%	72.3%	73.9%
Clinical outcomes				
Child growth (healthy BMI)		81.5%	83.5%	82.8%
Dental health (dmft > 0)[3]		44.4%	38.6%	42.1%
Dental health (dmft > 5)[3]		15.5%	15.6%	16.9%
Facial Growth (Good scores)		57.1%	53.9%	53.9%
Speech (Standard 1)[4]	-*	41.7%	53.7%	54.4%
Speech (Standard 2a)[4]	-*	65.0%	73.5%	73.7%
Speech (Standard 3)[4]		59.4%	62.0%	63.6%
Psychology (TIM 1a+)		87.8%	91.6%	90.9%

Response

POSITIVE STATUS

Positive outlier status for consent verification

This has been due to the diligent work of our cleft CNSs and our data coordinators who have worked together to register new patients with CRANE as soon as possible after birth and to highlight to each other those who need to be followed up.

NEGATIVE STATUS

Negative outlier for child growth data completeness

There is a lack of appropriate support staffing to undertake data capture during clinical appointments. In particular, the Great Ormond Street centre is unusual in not having a Clinical Co-ordinator. The Team continues to make a case to the Trust for this role to be created, as per the National Service Specifications.

Negative outlier for DMFT data collection for 2 consecutive reporting periods

The recording of calibrated DMFT data for the North Thames Cleft team is a long-standing problem (as previously reported) and dates to the unfortunate loss of 2 of our cleft calibrated paediatric dentists in close succession. We now have two consultant paediatric dentists in post but still have one on long term sick leave. This remains on the trust risk register and is the cause of this lack of data input.

As mentioned in previous years, from a governance perspective, it is important to highlight for the sake of the commissioners that a paediatric dentist (staff grade/registrar) or an orthodontist has carried out a detailed dental examination at the time of the audit appointment. All cases where dental disease has been detected have been referred to the patient's own dentist in primary care or internally for dental treatment to be carried out. We are happy therefore that the dental needs of our cleft patients are being managed.

Negative alert for 2 consecutive reporting periods, considered negative outlier: Speech Standards 1 & 2a

I have always been wary of any argument that variation in case complexity or speech therapy assessment was responsible for a disparity in outcomes between units. As Clinical Lead for the North Thames Service, I responded to our negative outlier status in 2024 for speech standards by saying that our speech therapy capacity did not match demand and that I also wanted to be open and to request an external assessment of our service.

As I write in 2025, again in response to a negative outlier status for speech standards 1 and 2a, our SLT capacity remains a concern. The CRANE workforce survey has shown that we have one of the lowest WTE SLT team staff numbers relative to caseload. We also see that many of our patients are unable to access local speech and language therapy under the age of 5 years, and we are unable to provide therapy for our patients in its absence. We are in the process of arranging a visit to assess our Service and I am grateful to the Cleft Development Group for their engagement and for identifying senior cleft colleagues who will undertake this.

Nevertheless, over the last 18 months I have spent a lot of time looking in detail at all the cases audited for speech in the birth range 2016 to 2018, which have led to this unit being a negative alert or negative outlier for three years consecutively for standard 2a – the structural, or by default surgical, measure of speech. My observations are:

- Like a lot of units, the COVID pandemic meant that very few patients in the birth cohort 2015 could be recorded and results from this year are hard to interpret.
- It has been a feature that a large number of children in North Thames are failing standard 2a due to nasal turbulence alone. Specifically, they have a nasal resonance score of normal or borderline and no history of fistula or palate revision, yet fail the standard due to turbulence alone. As a rule, these patients are not brought back to be assessed for revisional surgery and I am told that this is because their clinical assessment is of very acceptable speech.
- There appears to be a difference in how the CAPS-A audit tool is being applied, despite a national "calibration" of therapists and despite external listeners from nearby cleft units joining for a proportion of audit listening. I am not qualified to comment on the detail of this cleft speech therapy audit tool, but it appears to me that the most striking anomaly arises in the scoring of nasal turbulence. Having sought the opinions of senior cleft specialist speech and language therapists in our unit and elsewhere, it appears that nationally there is a degree of subjective application of a detail that if nasal turbulence is apparent in 10% or more of the target sentences then it is scored as "red" causing the standard to be failed. Similarly, there is disparity in the interpretation of the definition of turbulence being "pervasive or distinctive", which again appears subjective in its interpretation in different Cleft Services.

As a result of this I asked a question of the CRANE data team:

Compared to other UK teams, how many audit cases are failing only on nasal turbulence? (i.e. no other features of velopharyngeal incompetence). CRANE could not give details about individual units but compared us to the UK totals. The table below summarises this and shows North Thames cases failing on turbulence alone at a rate of 3 to 4 times that of other units. I find it difficult to accept as an accurate reflection of speech results that there should be such a specific anomaly. Although we would not be able to alter the data we submitted to CRANE, I have secured the assurance of our Trust that they will fund senior external listeners to reassess all of our 2018 birth cohort. To find out if there is truly a problem or if there is a difference in the process of assessment.

I remain committed to ensuring that no patient is being disadvantaged by having surgery in our unit and if the external listeners find the picture is correct then I will accept their assessment and ensure that changes are made.

		Standard 2a							
	Eligible cases with speech data	Met		Not met		Failed due to nasal turbulence only*		Failed with nasal turbulence=2 (red) & hypernasality <2 (green)**	
Unit	N	n	%	n	%	n	%	n	%
GOSH	90	62	68.9%	28	31.1%	7	25.0%	8	28.6%
Chelmsford	53	30	56.6%	23	43.4%	3	13.0%	4	17.4%
UK total	1308	961	73.5%	347	26.5%	21	6.1%	29	8.4%

*Red score (2) on Nasal Turbulence only and green scores on: hypernasality, hyponasality, nasal airflow, all three passive CSCs and no history of VP surgery or fistula repair.

**Nasal turbulence score 2 (red); Hypernasality score <2 (green). NB, other relevant CAPS-A speech parameters could be red too + history of VP surgery or fistula repair.

An internal review of these outcomes by our Lead Cleft Specialist Speech & Language Therapist has highlighted that "despite the Cleft SLT team's best efforts to adhere to a national auditing protocol, there is inconsistency in how units adhere to the reporting of the parameters therein. In our unit, environmental, staffing, and technical challenges have further compromised the quality and timeliness of our speech outcome reporting. Addressing these barriers is essential to ensure equitable and timely care for children within the cleft pathway, maintain national standards, and enable the service to fulfil its audit and reporting requirements without compromise."

As a final comment.

As a Cleft Surgeon I think that there is a wider discussion required as to whether an audit tool is fit for purpose if it marks equally the outcome for a child with mild turbulence affecting 10% of a speech sample and who does not require consideration for revision palate surgery - with that of a child who has had revision palate surgery and remains moderate or severely hypernasal.

I would urge our speech and language therapy colleagues nationally to reassess this audit tool, as well as the audit process. I know that many speech therapists have come to this conclusion before me and that in addition they would also wish a patient reported outcome to feature in national audit.

I must reserve judgement until a full review can be undertaken, but at present I do not think that we are representing national outcomes accurately.

Patricia Rorison

Consultant Cleft Surgeon
Clinical Lead
North Thames Cleft Service

Statement from Cleft Development Group and CRANE, with input from the Chair of Cleft Speech and Language Therapy (SLT) Leads Group, Chair of the Cleft Surgeons Clinical Excellence Network, Cleft Audit Protocol for Speech - Augmented Lead Trainers and Chair of the Cleft Quality Monitoring and Improvement Committee (QMIC)

Speech outcomes are assessed using the CAPS-A tool, which requires trained listeners to interpret and score speech recordings. For this reporting period (children born 2016-2018), the North Thames Cleft Service was identified as a negative outlier for Speech Standard 2A, as fewer children than expected achieved speech without structurally-related difficulties. Additional analyses revealed this was mainly driven by higher reporting of nasal turbulence. It is possible that this may reflect a different interpretation of the CAPS-A nasal turbulence parameter rather than true poorer outcomes, but independent verification to determine this will take time to complete. To ensure consistency and maintain confidence in the national audit, a temporary working group has been recommended to review how speech outcomes at 5 years of age are translated and applied to the CRANE Outlier Policy. Until this review is complete, the North Thames outlier status should be interpreted with caution.

9. The Spires cleft service

Notification of outlier status

Data items	Spires			
	Status	Cleft Service (%)	National Average (%)	Revised National Average (%)[1]
Consent verification	-	87.8%	92.5%	-
Data completeness				
Child growth	- -*	43.0%	51.2%	58.3%
Dental health (dmft)[2]		55.3%	55.7%	58.0%
Facial growth		46.2%	55.5%	61.4%
Speech		74.6%	69.5%	72.0%
Psychology (TIM)		77.6%	72.3%	73.9%
Clinical outcomes				
Child growth (healthy BMI)		88.8%	83.5%	82.8%
Dental health (dmft > 0)[3]		35.4%	38.6%	42.1%
Dental health (dmft > 5)[3]		12.1%	15.6%	16.9%
Facial Growth (Good scores)		50.0%	53.9%	53.9%
Speech (Standard 1)[4]		57.2%	53.7%	54.4%
Speech (Standard 2a)[4]		79.5%	73.5%	73.7%
Speech (Standard 3)[4]		62.8%	62.0%	63.6%
Psychology (TIM 1a+)	-	85.9%	91.6%	90.9%

Response

Thanks indeed for your letter dated the 15th August 2025 with regard to the CRANE 2025 Annual Report and the Outlier Notification process.

The Spires Cleft Service are confident in the accuracy of the data other than a small discrepancy in the percentage recorded for child growth. We would, of course, welcome external review if required as we are keen to learn from this process.

We have discussed the Outlier Notification at a recent Spires Network Meeting involving the entire multidisciplinary team and are pleased to provide a response to our negative alert status (for consent verification and psychology) and negative outlier status (for child growth).

Negative Alert: CRANE Consent Verification

This analysis covers those children born in 2016-2018 where Spires achieved a negative alert with an 87.8% consent verification compared to the national average of 92.5%. Closer scrutiny of the data over this time period demonstrates the following:

OUH	2016	2017	2018	Total
Consented	38	41	38	117
Declined	0	0	0	0
Unknown	5	4	4	13

SDH	2016	2017	2018	Total
Consented	30	45	36	111
Declined	2	0	1	3
Unknown	15	2	2	19

OUH & SDH	2016	2017	2018	Total
Consented	68	86	74	228
Declined	2	0	1	3
Unknown	20	6	6	32
TOTAL	90	92	81	263

Thus of 263 patients across the service, 231 patients had their consent status confirmed (i.e. consent accepted or declined) which amounts to 87.8%. Approximately 47% of the 'unknown' patients were Salisbury-based patients from the 2016 birth cohort; this figure is almost certainly exceptional as these patients would have attended for their 5-year Clinical Review Clinic in 2021. Historically this time-point would be used to confirm CRANE consent status; as these clinics were largely virtual in the post COVID-19 milieu of 2021 the opportunity to confirm CRANE consent would have been missed.

Our strategy to identify those patients who have an unknown CRANE consent status has since been modified such that when a cleft patient attends for any cleft-related outpatient appointment, the clinician receives an alert to flag that their CRANE consent status is unknown such that the parent (or legal guardian) can be approached if appropriate. The Salisbury and Oxford teams meet on a bimonthly basis to review the results of the Clinical Review Clinics for all patients who are five and ten years of age; as part of this process the CRANE consent status is confirmed and steps are taken to remedy those in whom consent is unknown.

We therefore anticipate that we will significantly improve on our CRANE consent capture rate for future reports.

Negative Alert: Psychological wellbeing

Thank you for highlighting the **negative alert** status for this metric which relates to TIM scores of 1a+ (i.e. seen by or having input from a Clinical Psychologist).

We have reviewed the data from the 2016-2018 cohort. We note that when no Clinical Psychologist was present in clinic there was some inconsistency in reporting for 2018 OUH births where, for some, no TIM score was recorded due to 'Lack of Staff / Facilities / Equipment' due to there not being a Clinical Psychologist present, whereas for others we had entered a TIM score (0d – Psychologist not present). We would value guidance from CRANE for the appropriate data point to enter for future years.

We note that our low TIM = 1 rate (n = 1) is in keeping with current CEN guidelines that all psychology input aged 5-6 years should be scored as TIM ≥ 2 and are therefore surprised by the high rate of TIM = 1 nationally.

A detailed review of our TIM data for patients where data is available (77.6%) has been conducted. A breakdown of this analysis is shown as follows:

	Oxford 2016	Salisbury 2016	Oxford 2017	Salisbury 2017	Oxford 2018	Salisbury 2018
0a	0	0	0	0	0	1
0b	0	0	0	0	0	0
0c	1	0	0	0	0	0
0d	1	0	2	3	9	7
0e	0	0	0	0	0	2
1	0	0	0	1	0	0
2	23	19	25	36	16	20
3	0	0	3	4	0	2
4	0	0	1	0	1	0
5	4	0	1	0	0	0
% 1a+	93%	100%	94%	93%	65%	69%

We note the high percentage of TIM = 1a+ data across both Oxford and Salisbury sites for 2016 and 2017 births. We note this is reflected in the 2015-2017 CRANE report, where we were a **positive outlier** for this metric.

We note the substantially lower percentage of TIM = 1a+ data across both Oxford (65%) and Salisbury (68%) for 2018 births.

Children born in 2018 would have been due for a 5-year review in 2023 and/or 2024. We have identified the following factors as likely having a negative impact on our ability to review 5-year-olds for audit for those children born in 2018:

- The sole Clinical Psychologist (Band 8a, wte = 0.64) on the Salisbury site was on maternity leave between August 2023 and September 2024. It was not possible to recruit maternity leave cover during this time, meaning that there was no Clinical Psychologist provision on site and that cover was provided by the Band 8c Clinical Psychologist (wte = 0.4) on the Oxford site and an interim Assistant Psychologist on the Salisbury site.
- The other Clinical Psychologist on the Oxford site (Band 8a, wte = 0.6) had an extended period of sick leave between December 2023 and September 2024. Again, this post was covered by the Band 8c Clinical Psychologist on the Oxford site.
- The Band 8c Clinical Psychologist on the Oxford site left their post in October 2024 and this post was not filled until February 2025.

Taken together there was a substantial reduction in the capacity of the Clinical Psychology team across both sites across large parts of 2023 and 2024. This is reflected in the high proportion of children born in 2018 scoring TIM = 0d across both sites and we believe this accounts for our lower than hoped for TIM = 1a+ rates for this birth year.

As of February 2025, we returned to full Clinical Psychology capacity across both sites so we are confident that TIM = 1a+ will return to previous rates for the 2019 birth cohort. However, we note that as our data was so heavily influenced by the 2018 birth cohort, we project that we are likely to remain at negative alert/outlier status for the duration that this cohort is included in the three-year reporting period.

This report and our subsequent review of both our data and Clinical Psychology resources across both sites has been a reminder of their being a single point of failure within our Clinical Psychology team on the Salisbury site where there is only one Clinical Psychologist in post – this means that business contingencies are challenging when the Psychologist is on leave. We are subsequently in the process of developing a business case for a Band 4 Assistant Psychologist post on the Salisbury site. We believe this would be a cost-effective solution that would substantially improve the capacity of the Salisbury Clinical Psychology team.

Negative Outlier: Child Growth

43.0% of CRANE consented children at Spires had a height and weight recorded at the age of 5 years which compares to a national average of 51.2% (and a revised national average of 58.3%).

This correlates to our Clinical Audit Review period of 2021-2023 (i.e. for the 2016-2018 birth cohort) with this metric now being a **negative outlie**r for three consecutive reporting periods. We have retrospectively examined our Spires data; over this period there were 232 CRANE consented patients who were audited across our service at the age of 5 years, of which 103 had both a height and weight recorded (44.4%). There were three patients in whom a weight was recorded but not a height. The proportion of patients who had a height and weight recorded was similar across the Salisbury (42.9%) and Oxford sites (45.7%).

A significant proportion of the 2021 Clinical Review Clinics were virtual on account of the COVID-19 pandemic thus height and weight were not measured. The recording of height and weight is undertaken by either the Play Therapist (in Oxford) or Cleft Clinical Support Assistant (in Salisbury). In Oxford our Play Therapist retired in July 2023; we were unable to recruit to this post until April 2025. Post-pandemic in Salisbury there was no Clinical Support Assistant until November 2022; they left the Service in November 2024 with a replacement appointed in April 2025. These gaps in covering our Clinical Review Clinics at both Spires sites meant that growth measurements were unfortunately incomplete.

We have now adopted a revised Data Collection Proforma for our Clinical Review Clinics on both the Salisbury and Oxford sites such that we can readily determine whether our audit data has been collected appropriately as well as enabling prompt assessment of the quality of our cleft outcomes. This data is reviewed on a bimonthly basis by the cleft multidisciplinary team on each site; our impression from appraising the 2025 data thus far is that we are

achieving a significant improvement in our child growth recordings.

Please do not hesitate to contact me should you have any further queries relating to our response to the Outlier Notification process.

Mr Marc Swan

Clinical Lead/Director

Spires Cleft Service

10. South Wales cleft service

Notification of outlier status

Data items	South Wales			
	Status	Cleft Service (%)	National Average (%)	Revised National Average (%)[1]
Consent verification		94.1%	92.5%	-
Data completeness				
Child growth	++*	88.5%	51.2%	58.3%
Dental health (dmft)[2]	++*	81.3%	55.7%	58.0%
Facial growth		82.4%	55.5%	61.4%
Speech		78.3%	69.5%	72.0%
Psychology (TIM)	++*	90.6%	72.3%	73.9%
Clinical outcomes				
Child growth (healthy BMI)	-	69.4%	83.5%	82.8%
Dental health (dmft > 0)[3]		36.8%	38.6%	42.1%
Dental health (dmft > 5)[3]		12.5%	15.6%	16.9%
Facial Growth (Good scores)		50.0%	53.9%	53.9%
Speech (Standard 1)[4]		48.9%	53.7%	54.4%
Speech (Standard 2a)[4]		76.0%	73.5%	73.7%
Speech (Standard 3)[4]		50.3%	62.0%	63.6%
Psychology (TIM 1a+)		96.6%	91.6%	90.9%

Response

Re: CRANE 2025 Annual Report - Outlier Identification

Thank you for your e-mail on the 15th August 2024 identifying the Welsh cleft lip and palate service for being a positive outlier in data completeness across two consecutive reporting periods for child growth, dental health, speech, and psychological (TIM scores). We are confident in the accuracy of this data and proud of the systems we have put in place to support data completeness. The reasons for our excellent results are multiple, I have highlighted a few key factors below.

- **Excellent administration support**: Our administration team go to great efforts to ensure all children are seen in clinic before their sixth birthday. At the start of the year, they identify all children requiring a five-year assessment, ensuring no patient is missed and all are appointed. They also follow up families to encourage attendance. This is further supported by a robust "Was Not Brought" policy which facilitates attendance at MDT appointments.
- **Designated five-year old audit clinics:** These clinics help staff consistently collect and record all required data. Recording outcomes on to the clinic sheets has now become routine practice for all team members.
- **Efficient data entry:** Our cleft team secretary inputs data onto the database at the time of typing the clinic letters, on a clinic-by-clinic basis. This regular approach makes the task manageable and ensures timely data entry.
- **Dedicated data inputting staff:** Our cleft team secretary, speech and language therapy assistant and assistant psychologist are responsible for data entry and highlighting missing data. They all are highly familiar with the CRANE database and attend the "Making it Better" sessions.
- **Psychology input:** Our clinical psychologist and assistant psychologist attend all MDT clinics enabling screening and input where necessary. This facilitates all psychology data to be collected.
- **Team-wide commitment to outcome reporting:** The entire team recognises the importance of reporting outcomes as a driver for improving patient care. We have demonstrated that by working well together, with good processes in place, and reflecting where progress can be made, we are able to deliver excellent results.

However, we were surprised to be flagged as a negative alert for clinical outcome scores for child growth (healthy BMI). This finding did not align with our clinical experience, as we have not observed a significant number of underweight children in our five-year old clinics. We have spent some time over the last few weeks, reviewing our local practice and processes.

The CRANE data highlights that 12 children (14.1%) were classified as underweight which was much higher than other units. Only 69.4% of our cohort had a healthy BMI compared to 81.3% to 89% in other UK units.

Our review included the following steps:

- We examined national Welsh data (2012-2019) which showed underweight rates among 4–5-year-olds ranging from 0.6 to 1%. The highest rate among health boards was 1.4%, suggesting a potential issue with the accuracy of our data.
- We approached CRANE to identify specific patients who were classified as underweight.
- Once identified, we reviewed the clinics these children attended. Two clinics stood out: one had 4 out of 5 children classified as underweight, and another had 3 out of 5. Clinical summaries indicated that none of these children were clinically underweight.
- I discussed this with the Dental Nurse Manager to understand how height measurements were being recorded. In previous years, we had consistent staffing with two or three named dental nurses. However, this year, due to staff sickness on the unit, consistency was lacking. It became evident that the height was being recorded incorrectly; dental nurses were taking the highest score not the correct score in the middle of the measurement. Therefore, some children's heights have been over inflated.
- While we can correct the data for identified children, others may remain inaccurately classified. Some children for example who have been recorded as having a normal BMI may, in fact, be obese. A full review of all the clinic records is required, which will take some time.

To address this issue, we have taken the following practical steps:

- Purchased a new measuring scale which displays a single reading.
- Provided training to dental nurses on how to take height measurements.
- Requested consistent staffing of dental nurses for the five-year-old clinics.

Although it is disappointing to discover inaccuracies in our height data, we are pleased that we have identified the root cause for our negative alert status and have implemented measures to rectify the issue.

Please feel free to contact me should you require any further information.

Helen Extence

Clinical Director
The Welsh Centre for Cleft Lip & Palate
South Wales Cleft Service

11. South West cleft service

Notification of outlier status

Data items	South West			
	Status	Cleft Service (%)	National Average (%)	Revised National Average (%)[1]
Consent verification	+	97.1%	92.5%	-
Data completeness				
Child growth	- -*	29.3%	51.2%	58.3%
Dental health (dmft)[2]	++	72.6%	55.7%	58.0%
Facial growth		44.4%	55.5%	61.4%
Speech	- -*	55.7%	69.5%	72.0%
Psychology (TIM)	- -*	62.2%	72.3%	73.9%
Clinical outcomes				
Child growth (healthy BMI)		89.6%	83.5%	82.8%
Dental health (dmft > 0)[3]		40.2%	38.6%	42.1%
Dental health (dmft > 5)[3]		22.6%	15.6%	16.9%
Facial Growth (Good scores)		33.3%	53.9%	53.9%
Speech (Standard 1)[4]	- -	31.7%	53.7%	54.4%
Speech (Standard 2a)[4]	-	58.9%	73.5%	73.7%
Speech (Standard 3)[4]	- -	39.9%	62.0%	63.6%
Psychology (TIM 1a+)	+	97.1%	91.6%	90.9%

Response

Notification of outlier status 2025 – UHBW response 29th September 2025

Since January 2024, following the SW Cleft service harm review, we have allocated funding for a member of the team to be responsible for data collection and input for the CRANE database. We are confident in the accuracy of data inputted and have reduced the amount of missing data from previous reporting periods.

While we know that our position for 2018 births and beyond will be improved due to changes in our processes, we acknowledge the service may continue to be a negative outlier for the next reporting period because of the time it will take for these changes to take effect and the fact that 2017 births, with higher incidences where data was not collected, will still be included in the report.

Reasons for outlier status are outlined below.

Data completeness measures

The number of audit clinics for 2016 and 2017 births was limited owing to the COVID-19 pandemic. Some clinics were able to take place in Bristol, however, many hospital sites where our peripheral clinics run were not willing to restart Cleft audit activity until later in 2022/2023 (Gloucester, Exeter, Plymouth, Truro). This accounts for the majority of patients recorded as “reason reported for not collecting data”. We are confident that as we move past this time period in the data it will show that we are within national averages for reporting complete data.

Dental Health (DMFT): This outcome is a positive outlier due to the fact that we were able to create capacity in the dental clinic as this posed less of a challenge compared with the multiple rooms and clinicians required to run each audit clinic.

Outcomes

Speech outcomes: Some children audited in this period were part of a cohort who experienced long delays waiting for primary palate repair, speech investigation clinic, and subsequent secondary speech surgery. All of the children who have failed speech standards have been looked at in detail to determine contributing factors. This includes waits for secondary speech surgery, and x ray investigation, along with other factors - clinical and social.

We would be open to receive feedback regarding our processes but are confident that we have put in place the following measures to improve our data collection and input in the future.

Following the SW Cleft service harm review 2024, funding for a data manager (0.4wte) was allocated as part of workforce planning. This has been filled since January 2025 by an existing member of the team. As of June 2025, we have successfully appointed a member of staff to this role on a fixed term basis for a year due to financial measures as a trust. The aim is still to appoint to permanent when the recruitment measures are stepped down.

In July 2025 we undertook a thorough review of audit clinic processes including a review of audit forms and clarification of responsibilities for data collection. There have been adjustments made to the data collection forms and to the clarification of responsibilities – including those of staff at Peripheral clinic sites who are not directly employed by the Cleft team. We hope to see continued improvement in the future reporting periods and a further reduction in missing data and reasons for not collecting data.

Due to the adjustments mentioned above, amendments to our whole MDT SOPs are underway to ensure that responsibilities are clear and new elements in the process are adhered to.

We have increased number of audit clinics in Bristol and at ‘spoke’ sites in the South West to ensure we have capacity to capture all patients at these clinics.

Following recommendations from the harm review, we have increased our workforce to support the extra clinic activity. A number of these are now in place, including extra speech and language therapy resource around the region.

Mr Mark Stevens, Deputy Divisional Director for Dental Services

Mr Shaheel Chummun, Consultant Cleft Surgeon

Mr Owen Ainsley, Divisional Director, University Hospitals Bristol & Weston

South West Cleft Service

12. Evelina London cleft service

Notification of outlier status

Data items	Evelina London			
	Status	Cleft Service (%)	National Average (%)	Revised National Average (%)[1]
Consent verification		94.3%	92.5%	-
Data completeness				
Child growth	- -*	25.2%	51.2%	58.3%
Dental health (dmft)[2]	- -*	46.5%	55.7%	58.0%
Facial growth		67.9%	55.5%	61.4%
Speech	- -	59.6%	69.5%	72.0%
Psychology (TIM)		74.2%	72.3%	73.9%
Clinical outcomes				
Child growth (healthy BMI)		87.3%	83.5%	82.8%
Dental health (dmft > 0)[3]	++	26.4%	38.6%	42.1%
Dental health (dmft > 5)[3]		14.4%	15.6%	16.9%
Facial Growth (Good scores)		65.8%	53.9%	53.9%
Speech (Standard 1)[4]		55.9%	53.7%	54.4%
Speech (Standard 2a)[4]		71.5%	73.5%	73.7%
Speech (Standard 3)[4]		59.5%	62.0%	63.6%
Psychology (TIM 1a+)	++	99.1%	91.6%	90.9%

Response

Many thanks for your letter of 15 August 2025 notifying us of the Evelina London Cleft Service's position relative to the other 12 regional cleft services in England, Wales and Northern Ireland with regards to key data items. It was also very helpful for me to have some additional correspondence with Dr Kate Fitzsimons (Senior Research Fellow) on 5 September 2025. Dr Fitzsimons who was able to provide us with additional data to allow us to have a deeper understanding of how our data completeness and outcomes have progressed over recent years.

For those copied in to this letter but not familiar with the Cleft Registry and Audit NEtwork (CRANE) Database and our relationship to it as a UK regional cleft service, the annual CRANE report refers to a range of indicators regarding registrations on the database and then adherence to standard processes in cleft care and clinical outcomes for children at 5 years old. The 2025 CRANE report will refer mainly to the cohort of babies born in the UK with a cleft in the years 2016-2018 inclusively.

Negative Outlier and Alert Status

You have identified that the Evelina London Cleft Service appears as a negative outlier or alert for just three areas – all of which relate to our 'data completeness' and not our clinical outcomes.

We were a negative outlier (more than three standards deviations from the national mean and outside the outer control limits of the funnel plot) for:

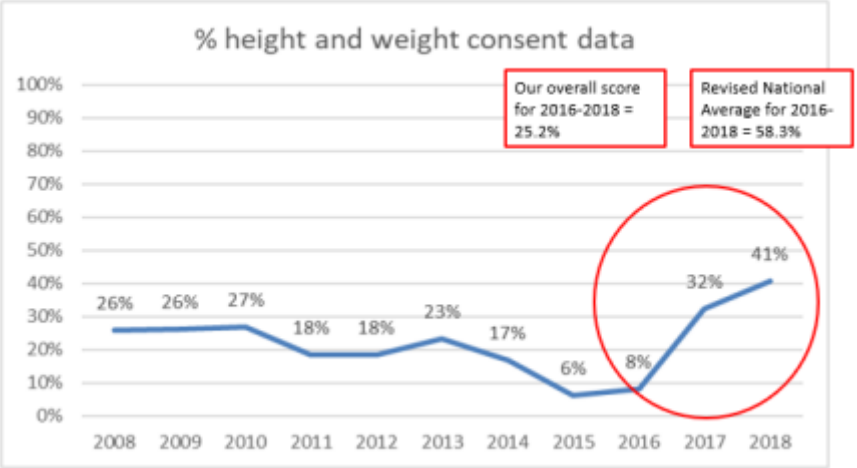
1. child growth (height and weight) – data completeness
2. dental health (dmft) – data completeness
3. speech (CAPS-A) – data completeness

I have studied the data in detail (hence my asking Dr Fitzsimons for additional information about the individual birth year cohorts) and we have discussed at length as a team, such that I am now able to provide an explanation about our outlier status for each of these metrics.

We appreciate that good data completeness is essential in order to allow us to interpret our data with confidence and are committed to providing as full a record as possible of the excellent care we provide for our patients. The CRANE report gives an average figure for a 'rolling' three birth year cohort. As a general point, it is fair to say that we have made substantial improvements in our data collection across all the aspects subject to CRANE's outlier policy (and those considered out with this) over the last three years. Data collection at 5 years for children born in 2016 was particularly problematic for us as a service, but I am delighted to say that we now have robust processes in place to ensure that we see children between their 5th and 6th birthdays and that we collect their multidisciplinary outcomes at that time point. Naturally, because of this rolling birth year cohort, it will take a little more time for our overall average scores to be within the funnel plot, but I am confident that by next year, we should have even fewer aspects in outlier status. It is, of course, our aim to have no negative outlier or alert status at all and we are working hard to achieve this.

1. Child Growth (Height and Weight) – Data Completeness

We are aware that the area where our data completeness is most inadequate is the collecting of height and weight data at 5 years. We continue to discuss and address this and are aware of a number of factors that contribute to our difficulties in this area. – including the challenges involved in getting reliable systems in place in outreach clinic locations where we need to seek support from staff and systems outside of those in our own NHS Trust locations. We have made some further changes to our practice this year – including adding a reminder to collect height and weight in our 'smartphrase' used for writing MDT clinic notes on Epic (the electronic patient record system used in our NHS Trust) and the year on year data that Dr Fitzsimons was able to provide us with has shown that we have further improved on our data collection from last year's report.

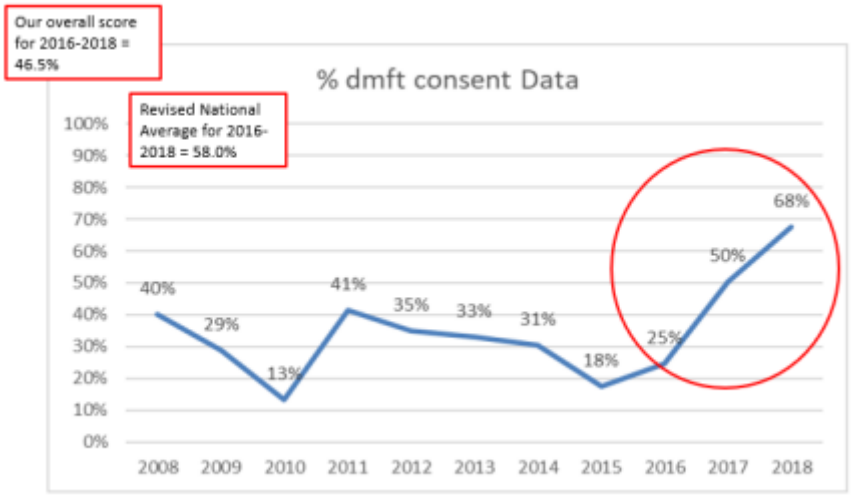


I am glad of the development of the Cleft Quality Monitoring and Improvement Committee (QMIC) and am a member of this group. It is helpful to see that services in other parts of the country do manage to collect a high proportion of child growth data and I am keen to speak with and learn from these teams about how they achieve good data completeness and to apply some of their strategies in our service wherever possible.

2. Dental Health (dmft) – Data Completeness

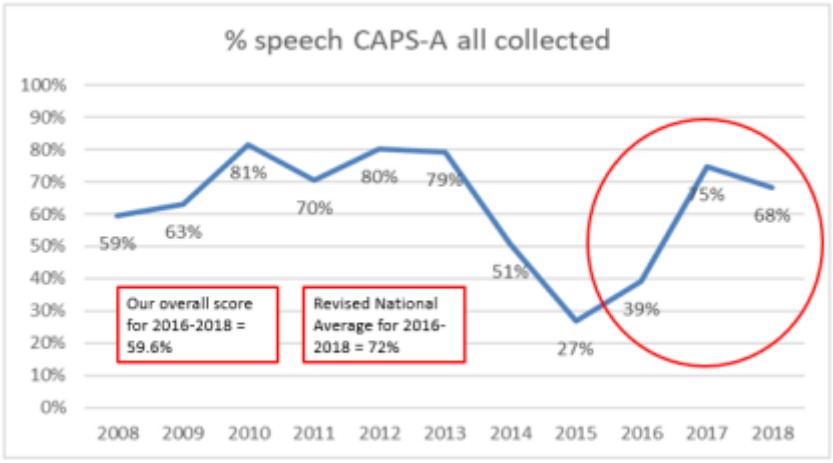
Here in Evelina London, we remain committed to supporting the dental health of children born with a cleft and a significant contributing factor to our ability to collect more complete data for recent birth cohorts, has been the appointment of a new Consultant Paediatric Dentist (calibrated to undertake and report on 5 year audits) to fill a vacant position. The previous post-holder experienced significant periods of sickness and we thus had reduced cover for quite some time. This, in combination with our historic difficulties in appointing children at the age of 5, means that our data completeness for collecting dmft scores has been poor in previous years. Although we remain an outlier when our three year data is considered, the year by year data that Dr Fitzsimons was able to supply shows that we have made substantial improvements in this area, to the extent that, for the 2018 birth cohort, our Paediatric Dental team were able to report a dmft score for 68% of eligible patients. This is actually higher than the current revised national average score for data completeness and we are proud of our achievements in this area.

We expect to come out of outlier status by next year when the data completeness figures will be based on children born in 2017, 2018 and 2019.



3. Speech (CAPS-A) – Data Completeness

This metric shows the proportion of eligible children in a given birth year who have had data uploaded to CRANE to show that they have been assessed, at 5 years of age, using the Cleft Audit Protocol for Speech – Augmented (CAPS-A). Our overall (average) score for the birth years 2016, 2017 and 2018 places us in negative outlier status and our year-on-year data suggests that we have seen a small reduction in our data completeness this year compared to last year's CRANE report.



I have discussed this matter at length with the Lead Speech and Language Therapist in the Cleft Service and also with our Audit and Information Officer to see if we can better understand this situation. Our concern is that there may be an issue with the accuracy of the data and we are looking into this further and will liaise with CRANE and national colleagues to ensure that our data – over all birth years – is as accurate as possible and so that we can be confident in how our data completeness is recorded. We believe there may be some inaccuracy in how many Evelina London Cleft Service patients have been marked as 'eligible' to be assessed using the CAPS-A. In calculating the denominator (the number of patients in a given year who would be appropriate to be assessed using the full CAPS-A) it is important to exclude those children with syndromes or those who could not participate in audit, and we will be undertaking a detailed analysis of how our denominator has been calculated. Our service records for numbers of 'eligible' patients are different to those reported by CRANE and we will be looking into this and liaising with CRANE to ensure that any issues are resolved so that we can all have full confidence in our data for this metric going forward. We expect that, by 2026 we will be out of outlier status for this area of data completeness as we now have good and robust processes in place to collect all of our data for 5-year-olds.

<u>Positive Outlier and Alert Status</u>

We were delighted to see that the Evelina London Cleft Service is not a negative alert or outlier for any of the outcome measures subject to the outlier policy. Indeed, we are shown to have achieved positive outlier status for two outcome measures.

1. Dental health at age 5 (as measured by dmft score)
2. Children seen by Clinical Psychology at the age of 5 (TIM score of 1+)

We are committed to providing comprehensive multidisciplinary care in the Evelina London Cleft Service and are delighted that our CRANE data shows that the outcomes we are obtaining for our patients are in line with and, in a number of areas, significantly higher than the national average.

Conclusion and Plans for the Future

The data collected by CRANE for the 2025 report emphasises that the Evelina London Cleft Service continues to provide excellent outcomes for patients in all aspects of multidisciplinary cleft care. This is testament to the hard work, high level of skill and dedication of the whole team and we are committed to a process of continual improvement.

As ever, we are hugely grateful to CRANE for the support and guidance they provide to us to collect the required data and for all the work that goes into analysing and reporting on this. We remain fully committed to this process of audit and improvement and continue to strive to do the best for our patients and their families. The development of the outlier policy and the creation of the Quality Monitoring and Improvement Committee (QMIC) have been positive developments in UK cleft care and we are glad to work with CRANE and the QMIC to understand how we can improve further and to support our national colleagues in their efforts too.

I am proud of the team and the work of the Evelina London Cleft Service and it is pleasing to see how our outcomes demonstrate what excellent, multidisciplinary, patient-centred care we provide.

Please do not hesitate to contact me if you have any questions or queries

Dr Kate le Maréchal

Consultant Clinical Psychologist and Head of Service
Evelina London Cleft Service

13. Northern Ireland cleft service

Notification of outlier status

Data items	Northern Ireland			
	Status	Cleft Service (%)	National Average (%)	Revised National Average (%)[1]
Consent verification	+*	100.0%	92.5%	-
Data completeness				
Child growth	+	72.7%	51.2%	58.3%
Dental health (dmft)[2]	++*	75.6%	55.7%	58.0%
Facial growth		50.0%	55.5%	61.4%
Speech		68.8%	69.5%	72.0%
Psychology (TIM)	++*	89.5%	72.3%	73.9%
Clinical outcomes				
Child growth (healthy BMI)		81.3%	83.5%	82.8%
Dental health (dmft > 0)[3]		39.4%	38.6%	42.1%
Dental health (dmft > 5)[3]		15.5%	15.6%	16.9%
Facial Growth (Good scores)	NP	37.5%	53.9%	53.9%
Speech (Standard 1)[4]		52.4%	53.7%	54.4%
Speech (Standard 2a)[4]		64.4%	73.5%	73.7%
Speech (Standard 3)[4]		64.6%	62.0%	63.6%
Psychology (TIM 1a+)	- -	63.6%	91.6%	90.9%

Response

Notification of Outlier Status – response

Thank you for identifying the Northern Ireland Cleft Service as a Positive outlier for data completeness in relation to Dental Health and Psychology and a negative outlier for clinical outcomes regarding Psychology (TIM1a+). We are confident that the data is accurate and are willing to receive an external review if deemed necessary.

Data completeness

Dental health (dmft) - This positive outlier status for dental heath reflects the impact of a streamlined approach effectively managed by our cleft coordinator. By ensuring that all children at age 5 have their multi-disciplinary team (MDT) review planned early, sufficient time is built into the pathway to prevent any risk of breaches in national requirements. In parallel, the dental surgeon is provided with the relevant CRANE data collection documentation in advance, facilitating accurate completion which is promptly added to CRANE, ensuring accurate, complete and timely recordkeeping.

Psychology (TIM) – following each audit clinic, the psychologist ensures a TIM score is collected and promptly recorded on a psychology database and onto CRANE. Data completeness is cross-checked by the psychologist and coordinator to ensure there is no missing or inaccurate data. When a psychologist has not been present for audit collection (due to staff illness, vacancy, leave etc) a TIM score of zero has been recorded with the appropriate code to account for this.

Clinical Outcomes
Psychology (TIM1a+) - It is noted that there was a high proportion of TIM scores of 0 (36.4% of patients) in the birth cohort 2016-2018 period.

The data has been checked for accuracy and it can be confirmed that the proportion of those scoring '0' is correct. In examining the periods of psychologist vacancy, the psychologist did discover one error in the database, in that 3 of the '0c' scores should have been recorded as '0d' (as there was no psychologist in post). This was due to a mistake in the psychology database. Overall, however, it can be confirmed that the number of zero scores were correct.

The service has explored why there was such a high proportion of TIM scores of 0. In the NI Cleft Service, we have one 0.6 WTE funded psychologist (0.3wte band 7, 0.3wte band 8a) assigned to cleft. Due to career progression following 18mths-2yrs post qualifying, often clinicians move to higher banded positions. Unfortunately, this has resulted in periodic vacancies, which has subsequently led to periods of no psychology screening for the birth cohort 2016-2018. Following discussions between the Cleft Service and the Paediatric Psychology Lead, a decision was taken to revise the capacity and banding structure in the hope of retaining staff. It is hoped that this will make a difference to psychology presence at cleft clinics where possible moving forward and therefore reduce the likelihood of negative outlier status in the future. Despite this, due to the nature of the reporting periods, it is estimated that psychology may remain a negative outlier for the next two reporting periods, due to the time periods where there was no psychologist in post. For instance, there was no psychologist available for audit collection between 01.01.21 – 01.03.21 and between 09.06.23 - 01.02.24 and again from 09.08.24 until 21.11.24. Following these reporting periods, however, it is expected that our TIM scores should be more in line with the rest of the UK centres. We welcome external review and any further suggestions for improvement.

Mrs Eilish O'Connor

Lead Speech and Language Therapist
Northern Ireland Cleft Service

14. Scotland cleft service

Notification of outlier status

Data items	Scotland			
	Status	Cleft Service (%)	National Average (%)	Revised National Average (%)[1]
Consent verification	--*	84.6%	92.5%	-
Data completeness				
Child growth	--*	27.9%	51.2%	58.3%
Dental health (dmft)[2]	++*	69.7%	55.7%	58.0%
Facial growth		77.4%	55.5%	61.4%
Speech		71.5%	69.5%	72.0%
Psychology (TIM)	++*	89.1%	72.3%	73.9%
Clinical outcomes				
Child growth (healthy BMI)		83.9%	83.5%	82.8%
Dental health (dmft > 0)[3]		38.4%	38.6%	42.1%
Dental health (dmft > 5)[3]		16.0%	15.6%	16.9%
Facial Growth (Good scores)		54.2%	53.9%	53.9%
Speech (Standard 1)[4]		55.2%	53.7%	54.4%
Speech (Standard 2a)[4]		79.6%	73.5%	73.7%
Speech (Standard 3)[4]		63.7%	62.0%	63.6%
Psychology (TIM 1a+)	++*	98.9%	91.6%	90.9%

Response

Thank you for your letter of 15th August 2025 notifying us of our outlier identification for the CRANE 2025 report. As per the outlier policy I am writing to confirm our:

- Confidence in the data.
- Willingness to receive external review.

For the five-year-old outcomes (children born 2016-2018) I am pleased to see our positive outlier status in data completeness from child dental health and psychology, and outcome for psychology.

In relation to our negative outlier status for consent verification and chid growth height & weight, as last year, I believe this outcome was predictable. Consents for children within this cohort have improved since last year's report (2015-2017 65.5%). They are however gained retrospectively through the hard work of our admin team and the wider cleft network in Scotland. At the time of submitting the data our verified figure was 84.6% but subsequently after further patient contact it is now above 90% for this cohort. I am hopeful this will continue to improve as we near the birth cohorts when Scotland joined CRANE (2023) and the consents process is part of our early contact.

In a similar manner we were not routinely taking weights and heights prior to joining CRANE, these can obviously not be collected retrospectively. Consequently, our figure is 27.9%. I am confident however through instigated systems and recruitment, this figure will improve once the birth cohorts match our date of joining CRANE.

Yours sincerely,

Toby Gillgrass

Clinical Lead for Cleft Surgical Service for Scotland
Scotland Cleft Service