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

2024 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 2015 and December 2017

On behalf of the Cleft Development Group

Responses to outlier process

In 2024, Cleft Services were notified of their outlier / alert status in relation to CRANE Indicators[1] on 20 August 2024.

The status of Cleft Services, for each key data item subject to the outlier policy, was listed in their Outlier Letter in a table using the **Key** below. Supplementary Tables with aggregate data at Cleft Service level were also provided, alongside the funnel plots used to identify alert and outlier status.

Cleft Services were notified of their outlier / alert status in accordance with the decision by the Cleft Development Group (CDG), to allow the Outlier Policy[2], piloted and introduced in 2021 to 2023, to become embedded in practice.

Indicators subject to the Outlier Policy currently pertain to the five-year-old cohort only (2015-2017 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 consecutive reporting periods (in 2023 and 2024), 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 the CRANE Database team about the reasons for the **outlier** status, as per the Outlier Policy agreed by CDG. Responses to indicators with **alert** status are not mandated but are welcome.

From 2025, Clinical Leads will be expected to provide full responses to outlier notifications. These will be published in a document such as this, alongside the CRANE Database 2025 Annual Report.

All responses provided to the 2024 outlier process are collated within the next pages of this document.

[1] Audit indicators as listed in the CRANE Database 2024 Annual Report: Supplementary tables - https://www.crane-database.org.uk/wp-content/uploads/2024/12/Annual-CRANE-2024-Audit-Report_Supplementary-tables_V1

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

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

Document	Published
CRANE 2024 Annual Report	December 2024
CRANE 2024 Annual Report: Supplementary tables (Appendices) (Excel Workbook)	December 2024
CRANE Outlier Policy[3]	March 2023

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

1. Newcastle cleft service

Notification of status

This cleft service was congratulated for being identified as a **positive outlier**, as well as being identified as a **positive alert** with regards to the following items:

Data items	Newcastle
Consent verification	++*
Data completeness	
Child growth (weight & height)	++*
Dental health (dmft)	++*
Facial growth (5-year-old index scores)	+
Speech (All 16 CAPS-A scores)	+*
Psychology (TIM)	++*
Psychology (SDQ)	++*
Outcomes	
Child growth (healthy BMI)	
Dental health (dmft>0)	
Dental health (dmft>5)	
Facial growth (Good scores)	
Speech (Standard 1)	
Speech (Standard 2a)	+
Speech (Standard 3)	
Psychology (TIM 1a+)	++
Psychology (SDQ high/very high scores)	

Response

I am happy that this positive outlier status(again) is to be shared with the Chief Executive of our Trust and be open to external review.

I have explained what I believe to be the reasons for our successes on many previous occasions. Much of it is down to excellent team-working, embedding audit and data collection into our service from the beginning, and being resourced to enable us to deliver excellent care.

Like many services I feel that there is more pressure than ever to remove resource from cleft. It is easy to forget the hard work that goes into maintaining excellence and falsely identify such services as sources of resource that can be taken and used elsewhere. Cleft services were well funded for a reason, and this must not be forgotten.

I note that these results are probably the last from a pre-COVID birth cohort, but I remain hopeful that our outcomes will continue to be good albeit with a different model of delivery.

I shall not be Clinical Lead of this service from 30/9 and have heard unofficially that David Sainsbury is taking over from that date. Please address future correspondence to him.

I am confident that David will take the Newcastle Cleft team forward and continue to improve on our previous successes.

Mr Peter Hodgkinson
Clinical Lead
Newcastle Cleft Service

2. Leeds cleft service

Notification of status

This cleft service was congratulated for being identified as a **positive outlier**, as well as being identified asa **negative alert** and **positive alert** with regards to the following items:

Data items	Leeds
Consent verification	++*
Data completeness	
Child growth (weight & height)	
Dental health (dmft)	
Facial growth (5-year-old index scores)	
Speech (All 16 CAPS-A scores)	
Psychology (TIM)	
Psychology (SDQ)	
Outcomes	
Child growth (healthy BMI)	
Dental health (dmft>0)	
Dental health (dmft>5)	
Facial growth (Good scores)	
Speech (Standard 1)	
Speech (Standard 2a)	-*
Speech (Standard 3)	
Psychology (TIM 1a+)	+*
Psychology (SDQ high/very high scores)	

Response

Response to the CRANE Database team regarding outlier identification within CRANE 2024 Annual Report including 2015-2017 births as follows:

<u>Consent verification – Positive outlier for 2 consecutive reporting periods</u>
This is credited to the clinical nurse specialists in the team and the team-dedicated Audit Administrator. The nurses would meet with parents in person to discuss CRANE in detail, leave the paperwork with parents to review and complete in their own time, and then collect this on a subsequent home visit.

<u>Speech (Standard 2a) – Negative alert for 2 consecutive reporting periods – considered negative outlier</u>

- **Speech data completeness**

The speech outcome data reported for Leeds represents two years of data (2016-2017) and not three years (2015-2017) as described in this CRANE Report 2024. The two years of data included and the consequent low proportion of eligible children with speech reported for Leeds (47/108; 43.5%) is due to the non-return of five year speech outcome audit data for 2015 births due to our service challenges associated with the impact of the Covid pandemic during 2020/2021. Although the numbers included for Leeds fall just within the lower 95% control limit (unlike two other units which were excluded from the calculation of the funnel plot due to data completion outlier status) we are concerned that the inter-unit comparison of Leeds with two years of data inclusion against other units with three years data inclusion is less reliable. Due to the considerable impact of the Covid pandemic on all health services especially during 2020, in retrospect it may have been relevant for CRANE to exclude all five year outcome data for 2015 births for all units.

- **Risk stratification**

There is no risk stratification applied to the data. The impact of risk factors including Robin sequence (RS) association and cleft type are now widely accepted. As reported previously by our unit in last year's report (2023)

the data particularly for 2016 births from our unit contained an unusually high proportion of less-favourable cleft palate type (72% less favourable CPO with extensive hard palate involvement). Internal review of our RS data in association with CPO, following the reported 6.5% rate in the Provisional CRANE Report 2024 showed an under-reporting of actual RS diagnosis from our unit. The data was fully reviewed and showed an incidence of 24% RS association which was then reported and included on the CRANE database in response to the Provisional CRANE Report 2024.
As this data is collected by CRANE and the relevance of such important risk factors on speech outcomes is undisputable, we are of the view that CRANE must introduce risk stratification for outcome measures as a matter of urgency and that the continuing annual reporting of non-risk stratified outcome data is unacceptable.

- **Process standards for speech audit**

The process standards for speech audit at five years of age include the requirement that a minimum number of five recordings per unit involve an external listener either as part of the consensus listening group or independently. The data included in this CRANE Annual Report 2024 states that of the 47 eligible children with speech reported, none of these (0.0%) were assessed by an external CAPS-A trained listener. This was due to the restrictions on our service caused by the pandemic and our consent process, which needed to be updated. For all units included in the Report, the percentage ranged from 0.0% to 100% (revised total 13.3%). Evidently, our unit was not alone in its inability to achieve this process standard for this birth cohort, and we acknowledge this limitation in our audit analysis process for this cohort.
We are concerned that due to the above reasons that the identification of our unit as a negative alert for speech Standard 2a is unreliable. Similar concerns were raised with CRANE by our team in response to the CRANE Report 2023 which to date have not been fully addressed. We therefore believe that it is unreliable for CRANE to consider our unit as a negative outlier for Speech Standard 2a based on the negative alerts for these 2 consecutive reporting periods (2014-2016, 2015-2017).

Psychology (TIM1a+) – Positive alert for 2 consecutive reporting periods – considered positive outlier
This reflects consistent presence of psychology at all MDT clinics to screen and provide input where necessary.

We thank you for this opportunity to respond to this CRANE report of outlier identification of our unit. The commitment of our unit in Leeds to national clinical audit is well documented and reflected in previous CRANE annual reports. However in response to the direct enquiry from CRANE within your letter of the 19th August 2024 regarding our confidence in the data, it is our view that due the reasons above that the CRANE reported data and analysis is significantly less reliable and reduces our confidence in the speech data contained within this CRANE Annual Report 2024. Nonetheless, we look forward to continuing working with CRANE and the Quality Monitoring and Improvement Committee to further improve the validity and reliability of our outcome data in Leeds and the broader national reporting.

Prepared by the Leeds Cleft Lip and Palate Service (27th September 2024).

Alistair Smyth, Lead Clinician/Cleft Surgeon
Samantha Calladine, Lead SLT
On behalf of the
Leeds Cleft Service

Context provided by CRANE

The CRANE Clinical Lead advised that there may have been some misunderstanding regarding what was agreed at the time of COVID and how CDG discussions / decisions were communicated to relevant CENs. CRANE operates under the guidance of CDG and there was discussion post COVID as to how CRANE would proceed in relation to which years should be assessed and reported. Discussion included the possibility of omitting certain years / extending the assessed period to include 4 years / or to return to the pre COVID standard of rolling three-year cohorts. CDG concluded that the latter should be followed. This decision was made on the understanding that the full outlier policy was to be introduced over a number of years, with no escalation of notification to Medical Directors and CEO's until 2025 at the earliest.

For 2015 births, 159/570 eligible children had complete CAPS-A data submitted and there was only one other unit who did not submit any speech data for their 2015 birth cohort. CRANE has looked at the 2016-2017 birth years in isolation and Leeds had 69% data completeness rate out of eligible cases (national average was 66%). The percentage of cases meeting each standard remain unchanged for Leeds as the denominator is children with

complete CAPS-A scores. For reassurance in the data, the range across units and overall averages for those meeting each standard are almost identical to those reported for the three-year birth cohort.

We acknowledge your frustration with the lack of risk adjustment. We fully intend to introduce risk adjustment for speech reporting in 2025, but this requires CDG sign off. Please be assured that our Clinical Lead will be recommending this to CDG in November 2024, for all patient characteristics collected by CRANE.

In terms of risk factors for poor speech outcome among children with speech data reported, CRANE can confirm that Leeds had:

- one of the highest rates of children with complete hard palate involvement among all CP, UCLP & BCLP cases (70% vs national average 56%)
- a relatively high proportion of children with complete hard palate involvement among those with CPO (46% vs national average 31%)
- a relatively high proportion of children reported to have PRS (17% vs national average of 12%)
- a relatively high proportion of boys (60% vs. national average 53%).

As communicated at the CFSGBI Conference in 2023, risk adjustment does not dramatically change a service's position on the funnel plot, but we acknowledge it does offer a fairer comparison between services, and that a small change in position can mean the difference between 'outlier' and 'alert' status or 'alert' and 'within the expected range'.

3. Liverpool cleft service

Notification of outlier status

This cleft service was congratulated for being identified as a **positive outlier**, as well as being identified as a **negative outlier** and **positive alert** with regards to the following items:

Data items	Liverpool
Consent verification	
Data completeness	
Child growth (weight & height)	+
Dental health (dmft)	
Facial growth (5-year-old index scores)	
Speech (All 16 CAPS-A scores)	
Psychology (TIM)	++
Psychology (SDQ)	++
Outcomes	
Child growth (healthy BMI)	
Dental health (dmft>0)	
Dental health (dmft>5)	
Facial growth (Good scores)	
Speech (Standard 1)	
Speech (Standard 2a)	
Speech (Standard 3)	
Psychology (TIM 1a+)	--*
Psychology (SDQ high/very high scores)	

Response

Thank you for highlighting the **negative outlier** status:
- **psychological wellbeing – TIM scores of 1a+, seen by or having had input from a psychologist**

Following the 2015-2017 CRANE preliminary report, we have reviewed the psychology data.

- We confirm that we are confident that the data is accurate with no modifications required.
- We would like to acknowledge that we are pleased to be positive outliers for data completeness for both our TIM and SDQ data.
- We would like to acknowledge we have striven to include as much data as possible, and to exclude as few as few patients as possible i.e. to provide partial data when SDQ data has been available, but TIM data has not.
- Please see below a detailed review of the TIM data for the reporting period:

	2015	**2016**	**2017**	**Total combined**
Total patients consented	64	79	57	200
Total patients with TIM	32	70	49	151
TIM 1a+	**19 (59.38%)**	**54 (77.14%)**	**39 (79.59%)**	**112 (74.17%)**

TIM 0	**13** **0a = 1** **0b = 1** **0c = 7** **0d = 4**	**16** **0d = 16**	**10** **0a = 2** **0c = 4** **0d = 2** **0e = 2**	**39**
TIM excluded with reason code	32 1 = (code 4) clinically contraindicated 31 = (code 9) not invited when 5	9 1 = (1) deceased or emigrated 3 = (2) patient transferred 2 = (6) patient cancelled/dna 3 = (9) not invited when 5	8 1 = (1) deceased 1 = (2) transferred into area 6 = (6) cancelled/dna appointment	49

- 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 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 are willing to welcome external review, in order 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

This cleft service was congratulated for being identified as a **positive outlier**, as well as being identified as a **positive alert** with regards to the following items:

Data items	Manchester
Consent verification	
Data completeness	
Child growth (weight & height)	++*
Dental health (dmft)	++
Facial growth (5-year-old index scores)	+
Speech (All 16 CAPS-A scores)	
Psychology (TIM)	++*
Psychology (SDQ)	
Outcomes	
Child growth (healthy BMI)	
Dental health (dmft>0)	
Dental health (dmft>5)	
Facial growth (Good scores)	
Speech (Standard 1)	
Speech (Standard 2a)	
Speech (Standard 3)	
Psychology (TIM 1a+)	+*
Psychology (SDQ high/very high scores)	

Response

Thank you for informing us of the **positive alert**.
Further to the recent Outlier Identification notification, as requested, I wish to provide a written response on behalf of the Manchester cleft team to confirm confidence in the data submitted and we're willing to receive external review.

The **positive outlier** status for data completeness for child growth, dental health, facial growth and psychology TIM is a reflection of a true team effort:

- our cleft coordinator works tirelessly to ensure the dataset is as complete as possible.
- our psychology assistants are really diligent in recording TIMs.
- the paediatric dental team (consultant and therapist) along with the supporting nursing team have modified the data collection sheet for audit clinics to include a section for recording of child growth and the dental nurses supporting the clinic routinely invite audit patients to have their weight and height recorded before they undergo their dental examination.
- Our dental therapist and cleft coordinator are both meticulous in their efforts to ensure all patients are contacted/invited to clinics and if appointments are missed, chase these up.

Mr Chris Sweet
Consultant Cleft, Oral & Maxillofacial Surgeon
Clinical Director, North West, North Wales & Isle of Man Cleft Network
Manchester Cleft Service

5. Trent cleft service

Notification of outlier status

This cleft service was congratulated for being identified as a **positive outlier**, as well as being identified as a **negative outlier, positive alert** and **negative alert** with regards to the following items:

Data items	Trent
Consent verification	
Data completeness	
Child growth (weight & height)	+
Dental health (dmft)	-
Facial growth (5-year-old index scores)	+
Speech (All 16 CAPS-A scores)	++*
Psychology (TIM)	–*
Psychology (SDQ)	–*
Outcomes	
Child growth (healthy BMI)	
Dental health (dmft>0)	
Dental health (dmft>5)	
Facial growth (Good scores)	
Speech (Standard 1)	++
Speech (Standard 2a)	++*
Speech (Standard 3)	++
Psychology (TIM 1a+)	+
Psychology (SDQ high/very high scores)	

Response

Thank you for your letter of the 19th August 2024. I would firstly like to thank all data capturers in cleft teams across the country and the CRANE team for collating and presenting the 2024 Report. The opportunity to use national data to help improve cleft services across the country is a unique privilege.

The Trent Cleft Network has been identified as a positive outlier in; data completeness in Child growth, Facial growth and Speech and for the outcomes in all three Speech standards and Psychology TIMs scores. The Network has been identified as a negative outlier for data completeness in psychology and dental health.

With a short word about the background to the region and the data I have presented our understanding of the reasons for these performances and our process for ongoing improvement.

Background

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

The birth cohorts audited in this 2024 report are from 2015 – 2017 and the audit data would have been captured 2020 -2022 and processed in 2021-2023. Some outcomes such as data completeness reflect relatively recent activity but some such as speech outcomes reflect activity of some years ago.

<u>Child growth</u>

The Trent Cleft Network received a positive alert for the amount of height and weight data submitted in this audit period.

I would like to thank the clinic nurses in our audit clinics for consistent data capture and the administrative team for their collation and reporting of this data.

Facial Growth
The Trent Cleft Network has received a positive alert for the amount of five year index data submitted in this audit period.

I would like to thank our team of orthodontists who have organised the audit clinics and encouraged our young patients to have dental models and photographs which provide this data. A particular thanks to our administration team for ensuring a high rate of clinic attendance and Ms Melanie Stern, our lead orthodontist, for her tireless work in data collation and analysis.

Paediatric Dental Health
The Trent Cleft Network has received a negative alert for the amount of DMFT data submitted in this audit period.

The Trent Team submitted DMFT data on a slightly higher proportion of our patients in the 2024 report period than in the 2023 report (an increase from 35% to 37%). Our transition from an average performer to a negative outlier reflects the improved submission levels from other teams across the country. We congratulate them on their performance and plan to improve our data capture in the future. (It is important to stress that this does not mean that our patients had very poor dental outcomes and the small quantity of data submitted shows our patients to have average DMFT scores for children with a cleft in the country.)

The Trent region has struggled in the national trend towards reducing availability of general dental services and particularly those commissioned by the NHS. The region also has areas where NHS dental services are, in practical terms, not available. This has placed a significant strain on the Community Dental Services to provide specialist paediatric dental care for children with a cleft.

Historically the Trent Cleft Network was not commissioned to provide children's dental services in all of our clinics. We are in discussion with the Nottingham University Hospitals NHS Trust about this issue and hope to work with commissioners from all the Integrated Care Systems which cover the region in extending specialist children's dental services. The expansion of the service will be funding dependant and, although we hope it will be achievable as soon as possible, any increase in the service will take several years to be reflected in the Annual Report.

Psychology
The Trent Cleft Network has received a negative alert for 2 or more consecutive reporting periods for the amount of TIM and SDQ data submitted in this audit period.

The Trent Cleft Network strives to provide all services as specified in the National Specification for Cleft Services and we are disappointed that we are a negative outlier in the completeness of TIMs and SDQ data submission. It is important to stress that this reflects our limited ability to collect audit data and does not mean that our patients had absence of psychological care or very poor psychological outcomes.

Historically the Trent Cleft Network did not have any psychology service within the team at all. A scoping exercise (2016 – 2018) conservatively suggested the service would need 2.4WTE (Whole Time Equivalent) psychologists to provide all clinical services and generate audit data. Nottingham University Hospitals NHS Trust and the East Midlands Specialised Commissioners agreed a staged investment plan in psychology and the Trent Cleft Network benefited by the creation of posts. We recruited to a 0.2WTE 8C leadership post in 2019 and 0.8WTE of a band 8A post in June 2022, but were not successful in recruiting to a 0.6WTE band 7 post. This post has subsequently been modified into 0.4WTE of band 8B time and following a long process we have just appointed a psychologist. In the interim, the incumbent of the band 8A post has taken maternity leave. The staffing level of psychologists within the team has therefore been well below the suggested 2.4WTE and the small amount of available resource has been focused on therapeutic interventions. Additionally, when we had an equivalent of 1.0WTE psychologist time, it became apparent that the estimation of 0.5WTE for adult services is well below what is actually going to be needed to address the needs of the adult patients in the service.

We are currently developing the core of our psychology service with additional appointments and ongoing service development. This work will involve the Trust and Commissioners across the Trent region and is likely to take several years to achieve a service which has capacity for audit data capture and processing in addition to delivering the therapeutic interventions needed by our patients. The need for one of our team to be off on maternity leave has also highlighted the vulnerability of a service which relied heavily on the input of a single practitioner. The enlargement of the team and the achievement of service security while supporting less than full time working

arrangements where needed is likely to be an ongoing process. The generation of audit data will follow this improved staffing but will take some years to be reflected in the Annual Report.

Speech
The Trent Cleft Network has been identified as a positive outlier in the completeness of speech data submitted for 2 or more consecutive periods and in the quality of outcomes in all three Speech Standards.

Thank you to all of our speech and language therapists for guiding parents, supporting children with speech difficulties, collaborating with community SLT and for the collaborative collation and analysis of speech data. A particular thanks to Lorraine Britton for her tireless work in development of the service, and data collation within our team and nationally.

The transition into better speech standard performance has been a broad process conducted over more than a decade. The process of ensuring babies are as healthy and ready for surgery as possible is thanks to our Nursing Team, Paediatricians and Anaesthetists. Surgically the use of evidence based procedures consistently delivered to a high standard has been an iterative and collaborative process. The introduction of early surgical outcome markers has been delivered by our Nursing Team and has informed surgical learning. The introduction of early speech assessment by our SLT Team and the close collaboration between SLT and surgeons has facilitated earlier intervention in children with speech difficulties. Thank you to all who have been involved in this ongoing process.

The Trent Cleft Network Team is committed to the delivery of high quality care for all patients with cleft lip and/or palate. All the members of the team deserve thanks for their commitment and dedication to this task. The success of our input is reflected across much of our work and our desire to continue to deliver high quality care and improve where possible is a strongly held value in our work. We hope to work closely with commissioners and our host Trust to continue to provide high quality service and to deliver improvement where needed.

Lastly, and most importantly, I would like to thank our patients and their families for their support for the CRANE audit process; for attending clinics, helping to provide audit data and for their input into the ongoing development and improvement of the service. Their courage, resilience and successes are a rich reward for our work.

Jonathan Syme-Grant
Clinical Director
Trent Cleft Service

6. West Midlands cleft service

Notification of outlier status

This cleft service was notified that they had been identified as a **negative outlier**, as well as being identified as a **positive outlier** and **negative alert** with regards to the following items:

Data items	West Midlands
Consent verification	-
Data completeness	
Child growth (weight & height)	--*
Dental health (dmft)	--
Facial growth (5-year-old index scores)	--*
Speech (All 16 CAPS-A scores)	--*
Psychology (TIM)	--*
Psychology (SDQ)	--*
Outcomes	
Child growth (healthy BMI)	**NP**
Dental health (dmft>0)	++*
Dental health (dmft>5)	++
Facial growth (Good scores)	**NP**
Speech (Standard 1)	
Speech (Standard 2a)	
Speech (Standard 3)	
Psychology (TIM 1a+)	--*
Psychology (SDQ high/very high scores)	

Response

Measures implemented since January 2024:

- Introduced structured 5-year audit clinics (4 full day clinics carried out to date)
- Created JD and PS for Data Coordinator post (and JE process now complete) - this has since been stopped and we are unable to advertise for this role, even though we have the finance
- New process agreed and implemented for obtaining consent in clinic
- Cleft Nurses validated A/N data and updated on CRANE
- Admin text reminders and phone calls to gain consent (2016-2017 births)
- Psychology has validated and entered all psychology data
- SLT team consensus listened to 2016 births and entered onto CRANE before end June 2024 deadline
- Planning and booking spreadsheet for 5-year-olds constructed and being used going forward
- Lead SLT works through all patients in each relevant birth cohort and identifies who is clinically appropriate for an audit clinic to streamline to process on the day

Potential Barriers to improving Negative Outlier Status:

Potential barriers to sustaining this and achieving target of not being a negative outlier for 2025 CRANE report:

- Not able to advertise and recruit to a permanent 'data coordinator' role. To date, IU and NM have been carrying all this out but that is unsustainable. Unless this post is recruited to, it will have on-going effects on every CRANE birth cohort year after year. This means:
  - no data entry
  - no management of audit clinics, appointments and coordination
  - no tracking of consent
- EPIC (Taurus) unable to link with CRANE
  - EPIC 1st rollout in mid 2025
  - will require the old database to be made fit for purpose and able to hold all the CRANE and outcome data for national reporting

- will continue to have separate spreadsheets not linked to patient records or Trust IT systems
- poor data entry or time-consuming duplicate data entry into a number of different databases and spreadsheets
- increased chance of human error in reporting

Additional issue with the current report is that it is the 2015 to 2017 birth cohort, which for 2015 translates to the 2020 audit year. We have no consent (or minimal) for 2015 births – 2020 audit data due to the Covid-19 Pandemic. It had previously been nationally agreed to not collect or enter the 2020 5-year audit data.

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

This cleft service was congratulated for being identified as a **positive outlier**, as well as being identified as a **negative alert** with regards to the following items:

Data items	Cleft Net East
Consent verification	
Data completeness	
Child growth (weight & height)	++*
Dental health (dmft)	++*
Facial growth (5-year-old index scores)	
Speech (All 16 CAPS-A scores)	
Psychology (TIM)	++
Psychology (SDQ)	++*
Outcomes	
Child growth (healthy BMI)	
Dental health (dmft>0)	
Dental health (dmft>5)	
Facial growth (Good scores)	
Speech (Standard 1)	-*
Speech (Standard 2a)	
Speech (Standard 3)	
Psychology (TIM 1a+)	++*
Psychology (SDQ high/very high scores)	

Response

I am pleased to see areas where Cleft.NET.East is performing above expectations. Regarding the single domain in which we are a below average outlier, and in response to your specific queries:

1. Confidence in the data. Our 2015 cohort data are impacted by the lack of Age 5 face-to-face assessment due to the COVID pandemic, resulting in missing data for 25 patients. Our 2016 and 2017 cohorts are complete, and therefore we have confidence in the validity of data for these years.
2. We are very willing and highly value insights from external review, and remain happy to participate.
3. Regarding our below expectations outcomes for Speech 1, we have reviewed the data internally and a large number of these are accounted for by anterior errors. These do not typically impact on the intelligibility of speech, and in our experience the young patients and their families report satisfaction with their speech and either decline to address minor differences or are not at an age where they can appropriately engage in therapy for this. Therefore, we do not consider that this negative outlier reflects a worse outcome that is meaningful to patients or their families. We are, however, constantly looking for ways to improve our performance and outcomes further, and I can confirm that actions we have undertaken since the report include:
    i. Further analysis of patient data and outcomes
    ii. Institute prospective data collection systems (including through EPIC) to detect issues early and sequentially evaluate our pathways
    iii. Prioritising 3 year assessments as face-to-face appointment to inform therapy requirement, and encourage all clinical staff to attend these clinics
    iv. Offer post-operative babble group universally as an early intervention group, rather than in a selective targeted manner, to promote accurate speech development and allow timely identification of any concern.
    v. Initiated discussions with community SLT services to improve access across our region aiming to improve access to timely needs led speech therapy intervention.

vi. Supporting and supplementing local (community) speech therapy services with therapy delivery, with blocks of intervention offered from the Hub team.

Ms Kana Miyagi
Consultant Plastic and Reconstructive surgeon
Clinical Lead

Hannah Chandler
Advanced Specialist Speech & Language Therapist
Cleft Palate & Velopharyngeal Dysfunction
Lead Speech and Language Therapist

Cleft.NET.East, Cleft Service

8. North Thames cleft service

Notification of outlier status

This cleft service was congratulated for being identified as a **positive outlier**, as well as being identified as a **negative outlier** and **negative alert** with regards to the following items:

Data items	North Thames
Consent verification	+*
Data completeness	
Child growth (weight & height)	++*
Dental health (dmft)	--*
Facial growth (5-year-old index scores)	
Speech (All 16 CAPS-A scores)	
Psychology (TIM)	++*
Psychology (SDQ)	++
Outcomes	
Child growth (healthy BMI)	
Dental health (dmft>0)	
Dental health (dmft>5)	
Facial growth (Good scores)	
Speech (Standard 1)	-*
Speech (Standard 2a)	-
Speech (Standard 3)	
Psychology (TIM 1a+)	--*
Psychology (SDQ high/very high scores)	

Response

Building on the response of my predecessor, and consulting with the there are members of the team the background I have compiled the following.
As a general comment, we still have difficulty in identifying patients to ensure that patients are appropriately brought to audit. The clinical team feel that there is a shortage of administrative support in the Great Ormond Street part of the service. We also have a shortfall in whole time equivalent speech and language therapists, paediatric dentists and there is no access to a psychologist within the MDT clinic.

POSITIVE STATUS

Positive outlier status for consent verification 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.

Positive outlier status for data completeness for weight and height is due to the early work of our cleft CNSs and the fact that we run centralised MDT clinics where height and weight are part of the standard check-in process for every child.

Positive Outlier Data completeness TIM scores: We believe the high completion rate of TIM scores is due to staff ensuring a score is given following a review appointment with the child. Where a psychologist has not been present in the audit clinic to provide the psychology cleft review, a score of 0 has been recorded to indicate the reasoning for the absence of psychology.
Positive Outlier Data completeness SDQ scores: We believe the high completion rate of SDQ scores is due to psychology questionnaires being sent to parents prior to their psychology appointment. Where a psychologist has been present in the audit clinic, they have been able to ensure that these questionnaires were completed, and a score generated.

NEGATIVE STATUS

Negative outlier TIM scores of 1a+: We note there is a high proportion of TIM scores of 0, indicating a psychologist was not present in clinic. We believe the majority of these scores were recorded for children born in 2015 under GOSH. We note that this birth year's 5 year audit co-indices with the COVID-19 pandemic in 2020. We believe the high rate of scores of 0, and thus lower rate of scores of 1a+, are a result of a lack of psychology presence in face to face clinics through the pandemic. Where children have not seen a psychologist in person as part of their 5 year review, the psychology team attempt to arrange the psychology review at a later date. Unfortunately, this can mean children are aged 6 by the time they are followed up by a psychologist and therefore their TIM score is not updated in time to submit to CRANE. There is a high DNA rate when appointments are offered outside of the MDT. North Thames are currently reviewing why patients are invited to attend their 5-year audit very close to their 6th birthday, which means that any cancellations or DNA's give insufficient time to re-book within the correct time-frame. Our admin team have identified some issues with our databases, which is currently being updated and addressed. We therefore hope to reduce the likelihood of outlier status in the future, with sufficient staffing and improved administration.

DMFT data outcomes: The recording of calibrated DMFT data for the North Thames Cleft team is a long-standing problem (as previously reported) and dates back to the unfortunate loss of 2 of our cleft calibrated paediatric dentists relatively close to one another. 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 my predecessor's report last year; 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 outlier for Speech Standard 1 and Negative Alert for Speech Standard 2a: I have reviewed my predecessor's response from last year, and worked with our speech and language therapists. As stated then, the main factor is the surgical outcome of velopharyngeal competence. Some of the birth cohort reported in this year's CRANE report include years where a significant number of children's speech records were not available for audit. This clearly raises some questions as to the accuracy of the outcome reporting.

As clinical lead, I undertook an exercise to identify the patients who were not reported on in each of these years using the clinical GOSPASS records as a proxy outcome measure. It was a difficult and time-consuming process to identify the relevant cases, but these clinical outcomes seemed to mirror those of the audited cases. This has been fed back to the team as a whole.

As stated in the response last year, there was a high usage of bio-materials (BioGide and PDS plate) by some, but not all, of the surgeons working during this time period. The question remains as to whether this contributed to these outcomes. There were also long periods of surgeon illness, meaning that in individual years a (different) single surgeon was reponsible for almost all of the workload. This inevitably made for a difficult working pattern and workload and raises the question of how a unit can manage what has become superspecialised surgery when the pool of trained surgeons is limited and great pressure can occur if one or perhaps two colleagues are unwell. Nevertheless, I would stress that we take these poor outcomes seriously and aim to make improvement. The Great Ormond Street Quality Assurance Unit are actively involved in assisting in the investigation of these outcomes and the outlier status is known at Trust Board level in both Gt Ormond St and Broomfield – meaning that a formal response is required into an action plan to rectify this.

In terms of what will be needed and how we will proceed. We would like to stress that administrative assistance will be required to improve our reporting. This means a dedicated Cleft Co-ordinator role and/or improvements in how the new electronic patient records (EPR) can be adapted to allow clinical staff to collect and submit audit data. I am pushing for an EPR project to improve this.

We also need to better fund our Speech and Language Therapists. There has been a turnover in staff, with new members needing time and funding to become CAPS-A trained. Issues relating to illness and a loss of clinical time for our new Lead have highlighted our relative lack of SLT provision compared to most other units. This is especially worrying at a time that we need to concentrate on monitoring and improving our speech outcomes.

As an immediate action, we have concentrated on identifying and prioritising the audit appointments of our 2018 cohort, so that we maximise our data reporting, making our next data submission more robust. This data will be internally reviewed as soon as it is available.

There are also now 2 surgeons in the unit who have joined since the cohorts who are being reported on in the 2024 report.

We would welcome a review of local practice if the initial evidence of the results for the birth cohort for 2018 does not show a significant improvement toward achieving the benchmark standards of 60% and 70% respectively for these speech outcomes.

Patricia Rorison
Consultant Cleft Surgeon
Clinical Lead

Psychology Response:
Amy Warren, Assistant Psychologist
Jo Shearer , Lead Psychologist

North Thames Cleft Service

9. The Spires cleft service

Notification of outlier status

This cleft service was congratulated for being identified as a **positive outlier**, as well as being identified as a **negative outlier** and **positive alert** with regards to the following items:

Data items	Spires
Consent verification	
Data completeness	
Child growth (weight & height)	–*
Dental health (dmft)	+
Facial growth (5-year-old index scores)	
Speech (All 16 CAPS-A scores)	
Psychology (TIM)	++*
Psychology (SDQ)	++*
Outcomes	
Child growth (healthy BMI)	
Dental health (dmft>0)	+*
Dental health (dmft>5)	+*
Facial growth (Good scores)	
Speech (Standard 1)	
Speech (Standard 2a)	
Speech (Standard 3)	
Psychology (TIM 1a+)	++*
Psychology (SDQ high/very high scores)	

Response

Thanks indeed for the Outlier Identification notice in advance of the CRANE 2024 Annual Report with respect to **'Percentage of Consented Cases with Height & Weight at 5 years'**.

This metric has now been a negative outlier for two consecutive reporting periods.

I have personally reviewed the data and can confirm that it is a true reflection of the data that we hold.

We would be very willing to be open to external review on this matter should you feel that this is necessary.

The circumstances of the outlier status for height & weight at 5 years are as follows and relates to the Salisbury hub of the Spires Cleft Service. During the zenith of the Covid-19 pandemic the suspension of in-person clinical audit clinic meant that this data was not collected across our service (i.e. neither the Salisbury or Oxford sites). 'Post-Covid' when F2F clinical review was re-established such that the clinical audit clinics were reactivated, the local Covid recovery protocol in Salisbury meant that the clinics were temporarily housed in a facility where the necessary equipment and personnel for recording height & weight were unavailable.

The Salisbury clinical audit clinic returned to the Children's Unit last year which also coincided with the appointed a new Clinical Support Assistant in October 2023. The Clinical Support Assistant is was responsible for taking height & weight measurements during the audit clinics.

A recent internal review of our Salisbury (and Oxford) clinical review clinics has demonstrated 100% compliance with height & weight measurements at 5 years indicating that the process issues that we experienced at the Salisbury site post-Covid have now been resolved.

Comments from the Spires Psychology and Dental teams regarding our positive outlier status:

a. Psychology Data Completeness for TIM & SDQ and Outcome TIM 1a+: Positive Outlier

Achieving positive outlier status for these parameters has been the result of a concerted effort from the Spires Clinical Psychology team in the face of the challenging circumstances resulting from the Covid-19 pandemic and staffing shortages.

However in order to maintain this performance going forward – including the addition of CLEFT-Q data at 10 years of age – the psychology team will require further support in terms of manpower. The pressures on the service have been relentless and have been compounded by staffing issues that render the balance between collecting audit data in a timely fashion and prioritising the waiting list for therapy and longer term interventions increasingly challenging.

b. Dental Outcomes: dmft scores >0 and >5: Positive Outlier

Spires is unusual in not having a Dental School within the region. Historically this has therefore required the ‘hub’ dental teams to develop strong collaborative working relationships with the ‘spoke’ Community Dental Services.

Not immune to dental deserts, Spires has a number of pockets of significant deprivation, however the importance of registration with a General Dental Practitioner is reinforced to families from the first point of contact (with coverage in our ‘Baby Book’ that all families receive). This message is reinforced at all subsequent appointments including the 18-month review, toddler clinic and 5-year linical audit.

Having said that, much of the Spires patch is more affluent and rural than many other UK centres, so it should be no surprise that our dmft scores reflect the national variation in dental decay (as outlined in the National Dental Epidemiology Programme for England report of 11th October 2023). In this sense we are in keeping with historic data from Spires. The Spires view has always been that comparing our dmft scores to different UK cleft centres is largely meaningless; until the Spires score is compared to the regional non-cleft scores then we cannot genuinely claim that having a better score is due to any specific factor other than geographical location.

Mr Marc Swan
Clinical Lead/Director
Spires Cleft Service

10. South Wales cleft service

Notification of outlier status

This cleft service was congratulated for being identified as a **positive outlier**, as well as being identified as a **positive alert** with regards to the following items:

Data items	South Wales
Consent verification	
Data completeness	
Child growth (weight & height)	++*
Dental health (dmft)	++*
Facial growth (5-year-old index scores)	+
Speech (All 16 CAPS-A scores)	++*
Psychology (TIM)	++*
Psychology (SDQ)	++*
Outcomes	
Child growth (healthy BMI)	
Dental health (dmft>0)	
Dental health (dmft>5)	
Facial growth (Good scores)	
Speech (Standard 1)	
Speech (Standard 2a)	
Speech (Standard 3)	
Psychology (TIM 1a+)	
Psychology (SDQ high/very high scores)	

Response

Thank you for identifying the Welsh cleft lip and palate service for being a positive outlier in data completeness for facial growth, and a positive outlier for 2 consecutive reporting periods for child growth, dental health, speech, and psychological wellbeing (TIM and SDQ). We are confident in this data and we are willing to receive external review.

The reasons for our excellent results are multiple:

- Through a series of staged investment we are now a fully funded service, this has ensured that we have a full establishment of team members who remain fully committed to this process.
- We have excellent administration support; the admin team go to great efforts to ensure all the five year olds are seen in clinic before they are six years of age. They constantly check and cross-reference with the CRANE database to see where there are gaps in our consent verification or data entry.
- We highlight all children who require a five year assessment at the beginning of the year, ensuring no patient is missed and everyone is appointed.
- Our admin staff chase families, so they attend. This is further supported by a clear “Was Not Brought” policy which helps patients to attend for MDT appointments.
- We have built audit and data recording into our processes. We have designated five and 10 year old audit clinics. Having designated clinics allows staff to remember everything we need to collect and record. Recording outcomes at clinics has now become routine practice for all team members.
- We have further tweaked our five year old proforma which is used at the designated five year old clinics. This has enabled us to record dental results and growth directly onto the proforma during the clinic rather than later searching through the medical note entries for the information. We have also added a section for syndromes. If we are unable to obtain the information, a reason is given at the time.
- Psychology (Clinical Psychologist and Assistant Psychologist) are present at all MDT clinics in order to screen and provide input where necessary. This facilitates all psychology data to be gathered.

- The dental nurse records height and weight measurements as a routine part of the appointment. We have two or three named dental nurses as this offers consistency, especially at times of annual leave or sickness.
- The cleft secretary inputs the information onto the database at the time of typing the clinic letters, inputting clinic by clinic. This makes it a manageable task as it is undertaken regularly.
- We have also found it helpful to have one or two staff inputting the data so it is consistent. We have identified our team secretary and our speech and language therapy assistant to do this, both are now very familiar with the CRANE database. They are responsible for identifying any missing data and to provide an explanation for this.
- Those identified to input information have received training from CRANE staff, they also have contact numbers to contact CRANE staff should difficulties arise. They both attend the “Making it Better” sessions.
- Whilst we fall within the 2 standard deviations for consent verification, this year we have successfully gained some consent that we previously had not managed to obtain by posting the consent forms out to families. This is credited to the dedication of our clinical nurse specialists in the team.
- I acknowledge it takes a huge amount of work and team effort to maintain excellent results. Many MDT staff have committed to not taking leave when there are five year clinics, this has facilitated all patients being appointed in the required time frame.
- I have been clinical director for six years and have offered stable leadership over this time which also contributes to the success of our outcomes. As a whole team, we recognise the importance of reporting outcomes as a means of driving improvements for patients. We have demonstrated that working well together, with good processes in place, and reflecting where progress can be made, we are able to deliver excellent results.

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

11. South West cleft service

Notification of outlier status

This cleft service was notified that they had been identified as a **negative outlier**, as well as being identified as a **negative alert** with regards to the following items:

Data items	South West
Consent verification	
Data completeness	
Child growth (weight & height)	–*
Dental health (dmft)	
Facial growth (5-year-old index scores)	–*
Speech (All 16 CAPS-A scores)	–*
Psychology (TIM)	–*
Psychology (SDQ)	–*
Outcomes	
Child growth (healthy BMI)	
Dental health (dmft>0)	
Dental health (dmft>5)	
Facial growth (Good scores)	**NP**
Speech (Standard 1)	-
Speech (Standard 2a)	
Speech (Standard 3)	-
Psychology (TIM 1a+)	
Psychology (SDQ high/very high scores)	-

Response

Please see below a response from the South West Cleft service to address the highlighted negative outlier status. 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 much 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.

Reasons for outlier status are outlined below.

Data completeness measures

- The service did not complete any audit clinics for 2015 births due to decisions made by the trust regarding clinical activity during the COVID-19 pandemic.
- The number of audit clinics for 2016 and 2017 births was also 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).

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.
- At the time, a harm review was conducted which concluded that children may come to harm because of delays in the service. This outcome data evidences this.

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 SW Cleft service harm review, funding for a data manager (0.4wte) was allocated as part of workforce planning. A member of the existing team has fulfilled this role since January, and we have successfully appointed to fill this post on a permanent basis.
- We undertook a thorough review of audit clinic processes including a review of audit forms and clarification of responsibilities for data collection and input.
- We are currently creating CRANE SOP for the whole MDT to ensure that responsibilities are clear.
- 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.

Ms Hannah Pickup
Performance and Operations Manager

Mr Alistair Cobb
Consultant Cleft and Maxillofacial Surgeon
Clinical Director
South West Cleft Service

12. Evelina London cleft service

Notification of outlier status

This cleft service was notified that they had been identified as a **negative outlier**, as well as being identified as a **positive alert** and **negative alert** with regards to the following items:

Data items	Evelina London
Consent verification	+
Data completeness	
Child growth (weight & height)	--*
Dental health (dmft)	--*
Facial growth (5-year-old index scores)	
Speech (All 16 CAPS-A scores)	-
Psychology (TIM)	
Psychology (SDQ)	-*
Outcomes	
Child growth (healthy BMI)	
Dental health (dmft>0)	
Dental health (dmft>5)	
Facial growth (Good scores)	
Speech (Standard 1)	
Speech (Standard 2a)	
Speech (Standard 3)	
Psychology (TIM 1a+)	
Psychology (SDQ high/very high scores)	

Response

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

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

- child growth (height and weight) – data completeness
- dental health (dmft) – data completeness

And we were flagged as a <u>negative alert</u> (between two and three standards deviations from the national mean and inside the outer control limit on the funnel plot) for a further two points:

- speech (CAPS-A) – data completeness
- psychological wellbeing (SDQ) – data completeness

This already represents an improvement from last year's report with one of these aspects (CAPS-A data completeness) moving from being an outlier to now only being an alert. In fact, all four of these areas have shown substantial improvement in terms of our success at data capture over the last three years:

Numerator	Percentage of eligible / crane consented children born in 2015 with the required data collected	Percentage of eligible / crane consented children born in 2016 with the required data collected	Percentage of eligible / crane consented children born in 2017 with the required data collected
Children with a recorded height and weight at 5 years of age ('Child Growth')	6.1%	7.9%	33.0%
Children with a recorded total dmft score at 5 years of age ('Dental Health')	17.5%	25.4%	50.5%
Children with recorded Cleft Audit Protocol for Speech – Augmented (CAPS-A) scores (all 16) at 5 years of age ('Speech')	27.0%	38.0%	72.4%
Children with a recorded SDQ score at 5 years of age	27.2%	36.8%	60.2%

The CRANE report gives an average figure for a 'rolling' three birth year cohort. We have made substantial improvements in our data collection across all the aspects subject to CRANE's outlier policy over the last three years and particularly for the 2017 birth year. However, it will take more time before our actions to improve data collection will be seen in our data completeness figures for the full three-year cohort represented within each annual report. The data collection process will continue to be our major focus with respect to CRANE.

In my letter to CRANE last year, I explained how we had analysed our processes and understood how it was that we had missed appointing children in the year between their 5th and 6th birthdays. I described the new processes we have put into place to identify children as they turn 5 and to ensure that they are booked into either a formal audit clinic or an MDT clinic before they turn 6 in order to allow all disciplines to collect the data required by CRANE. We now have this more robust system in place. I meet regularly (every 4 weeks) with our Audit and Information Officer and we minute these meetings and include action points that we refer back to at the following meeting. We review our audit appointment process in detail and I am confident that, in the fullness of time, our data completeness figures will reflect the hard work we are doing as a service to improve on our processes.

Collecting Height and Weight

We recognise that the area where our data completeness is most inadequate is the collecting of height and weight data at 5 years. This continues to be challenging for us – mostly in terms of getting reliable systems in place in outreach clinic locations where we do not have our GSTT team and where height and weight data collected by staff at the outreach location must be prompted by and then entered into the child's record in Epic by members of the cleft clinic MDT who are already busy completing their unidisciplinary and MDT roles. We are looking at how we can improve this further, but I am glad to see that we have quadrupled our rate of data collection already from last year and I expect that this will improve further year on year.

Collecting dmft (dental) data

Our Paediatric Dental team have shown some significant improvements in their data completion over the year (collecting double the amount of data for children born in 2017 compared to those born in 2016) but remain as a negative outlier for their ability to assess eligible children for dmft whilst they are 5 years old. Securing additional sessions of Consultant Paediatric Dental time in our service has been helpful, but it has taken time for this team member to be calibrated to collect the audit measurements, and then the Paediatric Dental team in cleft have experienced some issues with staffing firstly due to a team member reducing hours and then due to long-term sickness absence and now a post becoming vacant. Staffing issues play the largest part in causing our improvements in this area of data collection to be modest and are likely to continue to be problematic for some time to come. However, we have been able to recruit a full-time booking officer (administrator) to support the appointment of children to Paediatric Dental clinics and she is working closely with our Audit and Information Officer to ensure that eligible 5-year olds are prioritised for reviews and we expect that this will help us to continue to make progress with this domain.

Collecting CAPS-A (speech) data

As you know the main reason for our negative outlier and negative alerts for the Evelina London Cleft Service has been not bringing the children in for their audit appointment before they turn 6. This letter already clearly outlines the changes we have made as a service to put in place more robust systems to make sure that we are calling all 5 years olds in before they turn 6. Additionally, the data for 2015 and 2016 birth cohorts were particularly poor for speech, especially 2015, due to the timing of the COVID pandemic, as the patients who were seen on time were seen virtually in most cases, meaning that video recording could not be made and CAPS-A analysis could not be carried out. You can see a significant improvement in our data collection in 2017 (where we collected almost double the amount of data for children born in 2017 compared to those born in 2016), but this is not enough to

cause a significant improvement for the three-year cohort of 2015-2017. The SLT team are pleased to see this improvement and we have already moved from a negative outlier status to that of negative alert for our data collection. We are continuing to make improvements and we will continue to see improved rates of data collect for speech outcomes in our service.

Collecting SDQ (psychology) data

The Clinical Psychology team were disappointed to see that the collecting of SDQ data (where parents are asked to complete a 'Strengths and Difficulties Questionnaire' regarding their child's wellbeing) remains as a negative alert. Our data shows that Clinical Psychology in the Evelina London Cleft Service have reviewed almost 96% of all children in the three year cohort (those born in 2015, 2016 and 2017) by the time they reach the age of 6 (measured by having recorded a Tiers of Involvement Measure or 'TIM' score of 1-6) and it is likely that this has been achieved because, for the years when children turned 5 during the Covid-19 pandemic lockdown periods (in 2020 and 2021), we continued to review families virtually in online MDT and psychology led clinics. However, in that period, the giving and collecting of SDQ questionnaires was much more difficult to achieve –where these were sent online or via the postal service, the return rates were low. Similarly, to the other areas of data completeness discussed in this letter, our yearly figures show that the Clinical Psychology team almost doubled our rates of collecting SDQs for the 2017 birth cohort compared to those born in 2016. We expect that, now that the cleft service has put measures into place to bring all children to clinic (either to a formal audit clinic or a routine MDT clinic) during the year between their 5th and 6th birthdays, that our psychology data collection will increase too. We are fortunate to have the resource to be able to meet the standard of providing a Clinical Psychologist to attend every clinic hosted at our base or in outreach and this allows us to see and screen all children at 5 and to administer and collect the SDQ from their parents.

Conclusion and Plans for the Future

We are delighted to see that the Evelina London Cleft Service is no longer found to be a negative outlier or alert for any outcome measure for our patient cohort. The 2024 CRANE report shows that we are achieving clinical outcomes for our patient group for all aspects of their multidisciplinary care which are in line with or better than national averages.

There are areas of data completeness where we remain in outlier or alert status, but we have demonstrated improvements in all of these aspects and we expect that this will continue year on year with the new processes and oversight we have put in place.

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.

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.

Dr Kate le Maréchal
Consultant Clinical Psychologist and Head of Service
Evelina London Cleft Service

13. Northern Ireland cleft service

Notification of outlier status

This cleft service was congratulated for being identified as a **positive outlier**, as well as being identified as a **positive alert** and **negative alert** with regards to the following items:

Data items	Northern Ireland
Consent verification	+
Data completeness	
Child growth (weight & height)	++
Dental health (dmft)	++*
Facial growth (5-year-old index scores)	
Speech (All 16 CAPS-A scores)	
Psychology (TIM)	++
Psychology (SDQ)	++
Outcomes	
Child growth (healthy BMI)	
Dental health (dmft>0)	
Dental health (dmft>5)	
Facial growth (Good scores)	**NP**
Speech (Standard 1)	
Speech (Standard 2a)	
Speech (Standard 3)	
Psychology (TIM 1a+)	-
Psychology (SDQ high/very high scores)	

Response

<u>Data Completeness</u>

- Consent Verification (positive alert) - Consent information is given antenatally and at birth and revisited at home visit, time of surgery, EIC and any other opportunity for contact with parents. Consent form and SAE are added to Cleft Pack and returned to CNS who inputs onto CRANE as soon as received.
- Child Growth (positive outlier) – height and weight are taken when children attend Early Intervention Clinic aged 6 months +, these are then added to CRANE by CNS. CNS attends all 5y JCPCs and gets measurements and adds to CRANE on the day. She checks all the 5y attendees' 1 year outcomes and if not on CRANE, CNS contacts the relevant Child Health Department and adds them in retrospect (all children will have had either a 6-9m or a 1year Health Visitor review so growth should be recorded on these).
- Dental Health (Positive Outlier for 2 consecutive reporting periods) – Dentist is given CRANE Age 5 Data Collection form for each patient on the morning of clinic, after Audit clinics, Coordinator inputs data onto CRANE as per consultant dental surgeon to ensure information is uploaded accurately on every patient who attended that day, avoiding missing or incorrect data being added.
- Psychology TIM & SDQ data (positive outlier) – following audit clinic, Psychologist inputs data onto CRANE, this is then cross checked by our Cleft Coordinator and Psychologist prior to CRANE deadline for reporting to ensure there is no missing or inaccurate data.

<u>Outcomes</u>

- TIM 1a+ (negative alert) – in NI cleft unit we have 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 lowered levels of psychology screening for the birth cohort 2015-2017. Following discussions between the Cleft team and the Paediatric Psychology Lead a decision was taken to revise the capacity and banding structure in the hope of retaining staff.

Mrs Eilish O’Connor
Speech and Language Therapist

Mr Chris Hill
Clinical Lead/Director
Northern Ireland Cleft Service

14. Scotland cleft service

Notification of outlier status

This cleft service was congratulated for being identified as a **positive outlier**, as well as being identified as a **negative outlier** and **positive alert** with regards to the following items:

Data items	Scotland
Consent verification	--
Data completeness	
Child growth (weight & height)	--
Dental health (dmft)	++
Facial growth (5-year-old index scores)	+
Speech (All 16 CAPS-A scores)	++
Psychology (TIM)	++
Psychology (SDQ)	++
Outcomes	
Child growth (healthy BMI)	
Dental health (dmft>0)	
Dental health (dmft>5)	
Facial growth (Good scores)	
Speech (Standard 1)	
Speech (Standard 2a)	
Speech (Standard 3)	
Psychology (TIM 1a+)	++
Psychology (SDQ high/very high scores)	

Response

Thank you for your letter dated 19th August 2024 notifying us of our outlier identification for the CRANE 2024 report.

I have had the chance to share the letter to the Cleft Surgical Service for Scotland and members of the Cleft Care Scotland Managed Clinical Network.

As per the outlier policy I am writing to confirm our:

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

For the years chosen (2015/2016/2017) we are clearly encouraged with our positive outlier position for data completeness for those noted (dental health, facial growth, speech, and psychology) and the clinical outcome for psychology.

In relation to our negative outlier status for consent verification and child growth height and weight, we believe this outcome was predictable. Despite our admin and nursing team's best efforts, we have had to gain consent retrospectively. We were also not routinely taking weights and heights prior to joining CRANE. We are confident however; we now have systems in place to achieve this.

Toby Gillgrass
Clinical Lead for Cleft Surgical Service for Scotland
Scotland Cleft Service