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Promoting excellence in cleft care

CLEFT REGISTRY & AUDIT NETWORK



Cleft Registry and Audit NETWORK Database

Part of the Clinical Effectiveness Unit, of the Royal College of Surgeons of England

2023 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 2000 and December 2022

On behalf of the Cleft Development Group

Responses to outlier process

In 2023, Cleft Services were notified of their outlier / alert status in relation to CRANE Indicators¹ on 24 August 2023.

Cleft Services identified as **positive outliers / alerts** were not obliged to respond to notification of their outlier / alert status.

This was in accordance with the decision by the Cleft Development Group (CDG), to allow the [Outlier Policy](#), piloted and introduced in 2021, to become embedded in practice.

Cleft Services identified as **negative 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.

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 2025 Annual Report.

All responses provided to the 2023 outlier process are collated within the next pages of this document.

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

Document	Published
CRANE 2023 Annual Report	December 2023
CRANE 2023 Annual Report: Supplementary tables (Appendices) (Excel Workbook)	December 2023

¹ As per the CRANE 2023 Annual Report and Supplementary tables

1. Newcastle cleft service

Notification of status
<p>This cleft service was congratulated for being identified as a positive outlier with regards to:</p> <ul style="list-style-type: none"> • consent verification* (*for 2 consecutive reporting periods) • child growth (height and weight) – data completeness* • dental health (dmft) – data completeness* • speech – data completeness (CAPS-A)** (**a positive alert for 2 consecutive reporting periods) • psychological wellbeing (TIM) – data completeness • psychological wellbeing (SDQ) – data completeness • speech – standard 2a, speech without difficulties resulting from existing or previous structural anomalies <p>This cleft service was also identified as a positive alert with regards to:</p> <ul style="list-style-type: none"> • psychological wellbeing – TIM scores of 1a+, seen by or having had input from a psychologist
Response
<p>I am happy to respond to the positive outlier status of the Newcastle Cleft Team.</p> <p>The reasons for our outstanding results are multiple.</p> <p>The team was set up following a full assessment of the needs of our local population and the required resources. We were fortunate to be fully funded and set up our team appropriately.</p> <p>We built audit and data recording into our processes at a fundamental level and because we identified the need to record outcomes, this area of our practice has also continued to be complete.</p> <p>We have encouraged research and innovation. All the evidence supports the concept that involvement in research in any area of medicine improves outcomes. This has given us the opportunity to develop and modify treatments that have led to improvements in surgery, speech therapy, dentistry, orthodontics, etc.</p> <p>We are a very integrated and stable team.</p> <p>I have been clinical lead for 20 years. I have come to the conclusion that stability of leadership probably also contributes to the success of the team.</p> <p>In general, though our outstanding results illustrate what can be achieved by a stable team, working well together, recording, and reflecting on outcomes for the benefit of our patient group.</p> <p>Mr Peter Hodgkinson Clinical Lead Newcastle Cleft Service</p>

2. Leeds cleft service

Notification of status
<p>This cleft service was notified that they had been identified as a negative alert with regards to:</p> <ul style="list-style-type: none"> • speech – standard 1, speech with no evidence of a structurally related problem and no cleft speech characteristics requiring intervention • speech – standard 2a, had speech without difficulties resulting from existing or previous structural anomalies • speech – standard 3, speech without cleft-related articulation difficulties <p>We also congratulated them for being identified as a positive outlier with regards to:</p> <ul style="list-style-type: none"> • consent verification* (*for 2 consecutive reporting periods) • psychological wellbeing – TIM scores of 1a+, seen by or having had input from a psychologist** (**a positive alert for 2 consecutive reporting periods) <p>This cleft service was also identified as a positive alert with regards to:</p> <ul style="list-style-type: none"> • Psychological wellbeing – high/very high SDQ total scores, indicating difficulties.
Response
<p>Response to CRANE Database team regarding negative alert/positive outlier/positive alert identification within CRANE 2023 Annual Report (2014-2016 births). Comments/Response from Leeds Cleft Unit:</p> <p><u>Negative alerts for speech standards 1, 2a and 3</u></p> <ul style="list-style-type: none"> • Speech data completeness <p>Four units nationally (West Midlands, Cleft Net East, South West and Evelina London) were identified as negative outliers as their rates of data completeness fell below the 99.8% lower control limit and these units were therefore excluded by CRANE from the generation of the funnel plots. The generation of the national funnel plots (2014-2016) is based upon less than 50% of the consented eligible cases that had all 16 CAPS-A scores recorded. Exclusion of the speech data from four units and the overall low level of speech data inclusion (all 16 CAPS-A scores) with a total of eight units (including Leeds) below 50% suggests that the funnel plots for speech outcomes are generated from 41% (599/1438) of eligible consented cases nationally. This relatively low level of overall speech will influence the validity of the funnel plot calculations and individual unit positions. With respect to the data completeness for Leeds, this is also low at 42% and this does not include a 3-year period of data as 0% data was submitted for 2015 births from our unit due to the impact of Covid on national services. If 2015 CRANE consented and verified patients are included in the overall report (2014, 2015, 2016) then the Leeds speech outcome data is based upon 47 patients from a total eligible cohort of 119 (39%). The speech data for Leeds represents 42% of eligible patients from a non-consecutive two year period (2014 and 2016) and not a three year period of speech data submission.</p> <ul style="list-style-type: none"> • Risk stratification <p>Although CRANE have previously demonstrated the relevance of cleft palate type linked to speech outcome measures including extent of cleft palate involvement and PRS there is no risk adjustment included within the CRANE analysis of 2014-2016 births. Internal review of the Leeds speech data for the 2016 births cohort submission shows a high proportion of less-favourable extensive forms of isolated cleft palate (72%) and consequently a low proportion (28%) of patients with a more-favourable CPO presentation. The figure of Robin Sequence (RS) association for Leeds (9.1% 7/77 consented children with CPO) is lower than expected. We assume that this figure of 77 consented patients includes 2015 births for which no speech outcomes were submitted at all. Our records show that eight patients alone in 2014 and 2016 (not including 2015) had RS association and therefore the incidence of RS should be higher. Within the report, cleft type presentation and rates of RS are presented for consented patients. It would support our interpretation of speech outcome data to have access to cleft type presentation and RS rates for the subgroup of patients who have a reported speech outcome.</p> <ul style="list-style-type: none"> • Process standards for speech audit <p>One of the process standards was not fully achieved for Leeds speech audit reporting in 2016. The process standards developed nationally state that a minimum of five consecutive recordings per unit involve an external listener either as part of the consensus listening group or independently. It is assumed that this level of additional quality control is relevant and important to the accuracy of speech outcome data and confidence with that data.</p> <ul style="list-style-type: none"> • Inclusion/exclusion criteria <p>CRANE guidance on recording syndromes and additional diagnoses was updated in March 2021. The team in Leeds has taken care to ensure it has followed this guidance accurately. However, they would value an opportunity to</p>

discuss the classification of some diagnoses. This is important to ensure all units are implementing the guidance consistently and thus providing truly comparable data.

- **Nature of speech difficulties and intervention provision**

In the birth years 2014 and 2016, 27 children had a speech profile that did not meet one or more of the national standards. Surgical intervention was recommended for 19 children. Twelve (12/19; 63%) children had received surgery prior to their speech assessment at age five; 7/19 (37%) had not. Six (6/12; 50%) of the children who had received surgery prior to age five were subsequently listed for a second speech procedure. Internal analysis shows that the length of the pathway from identification to surgical treatment is a factor that may have accounted for persisting speech difficulties at age five. The service implemented changes in 2018 that resulted in efficiencies within this pathway for children born in 2016 (onwards). However, these gains were masked by the impact of the pandemic and associated resource constraints. Therapy intervention was recommended for 22 children. Articulation difficulties had resolved in three children by age five and persisted beyond age five in 19/22 (86%) children. Internal investigation has considered a range of factors that may account for persisting articulation difficulties, such as availability of therapy provision, level of attendance at appointments, structural constraints, and additional difficulties (such as delayed listening/attention, hearing loss). Structural constraints and additional difficulties feature highly in the 19 children who required further therapy beyond age five. The pandemic had an impact on the availability of therapy for some children.

A small but significant number of children had speech differences that meant they did not achieve national speech standards at age five, but these were mild and not having a negative impact on the children, so neither surgery nor therapy intervention was recommended. This reflects the significance of holistic assessment and individual factors when making decisions about treatment.

The Leeds team is exploring how best to measure the effectiveness of interventions they provide to children born with cleft palate and/or lip. One project is already underway examining speech outcomes and prognostic factors relating to the surgical intervention of palate re-repair. Measuring the effectiveness of therapy intervention is more complex, in part because intervention provision is shared between the specialist team based at the cleft unit and community SLT services, which are more proximal to the child/family. The SLT team has developed and implemented a framework for classifying specialist provision based on the goals of therapy. This will support the evaluation of therapy when suitable measures have been developed.

Positive outlier for consent verification

This is credited to the clinical nurse specialists in the team. 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.

Positive outlier for psychological wellbeing (TIM scores)

This reflects consistent presence of psychology at all MDT clinics to screen and provide input where necessary.

Positive alert for psychological wellbeing (SDQ scores)

This data is likely skewed in a positive direction by the incomplete screening data provided during the pandemic. The 2015 cohort, who didn't attend an MDT clinic, when possible, were seen separately by psychology. The SDQ was only administered when there was time within the appointment to do this. This resulted in only those families who reported no/minor issues completing an SDQ.

Prepared by the Leeds Cleft Lip and Palate Service (26th October 2023).

Alistair Smyth, Lead Clinician/Cleft Surgeon
 Samantha Calladine, Lead SLT
 Andrea Gaston, Consultant Clinical Psychologist
 Emma Blair, Lead CNS
 Rachel Dalton, Audit Administrator
 Colin Holton, Clinical Director, The Leeds Children's Hospital
Leeds Cleft Service

3. Liverpool cleft service

Notification of outlier status
<p>This cleft service was notified that they had been identified as a negative outlier with regards to:</p> <ul style="list-style-type: none"> • dental health (dmft) – data completeness* (*a negative alert for 2 consecutive reporting periods), and • psychological wellbeing – TIM scores of 1a+, seen by or having had input from a psychologist <p>This cleft service was also identified as a positive alert with regards to:</p> <ul style="list-style-type: none"> • Psychological wellbeing (TIM) – data completeness.
Response
<p>Thank you for informing us of the positive alert with regards to:</p> <ul style="list-style-type: none"> • Psychological wellbeing (TIM) – data completeness. <p>We are pleased to have been successful in achieving high levels of data completeness in relation to our psychological wellbeing measure.</p> <p>With regards to the negative outlier status identified:</p> <ul style="list-style-type: none"> • dental health (dmft) – data completeness* (*a negative alert for 2 consecutive reporting periods) <p>Having reviewed the data available on CRANE and locally we have identified an issue with the process for inputting the dmft data onto CRANE in Liverpool. We noted data had not been inputted if the child had been seen by a calibrated dentist out with the 5 year audit clinic. This data was available locally. Changes have now been made to this process. The consultant paediatric dentist and audit coordinator will now meet in January of each year to ensure all available data is inputted to CRANE.</p> <ul style="list-style-type: none"> • psychological wellbeing – TIM scores of 1a+, seen by or having had input from a psychologist <p>We have identified the following factors that have unfortunately impacted negatively on our ability to review 5 year olds face to face for audit:</p> <ul style="list-style-type: none"> • Changes to usual MDT clinic structure during COVID-19 (e.g. 5 years olds being seen out with dedicated audit clinics, and in virtual rather than face to face clinics) • Lack of Clinical Psychology resource (i.e. due to annual leave, sickness, and lack of maternity leave cover for the period between April-October 2021) <p>We are hopeful that with recent resumption of MDT and Clinical Psychology services that future difficulties collecting audit data face to face will be avoided, but we are currently undertaking a review and considering the need for additional Clinical Psychology resource in order to ensure resilience and high performance within our service.</p> <p>Mr Chris Sweet Consultant Cleft, Oral & Maxillofacial Surgeon Clinical Director, North West, North Wales & Isle of Man Cleft Network Liverpool Cleft Service</p>

4. Manchester cleft service

Notification of outlier status
<p>This cleft service was congratulated for being identified as a positive outlier with regards to:</p> <ul style="list-style-type: none"> • child growth (height and weight) – data completeness* (*for 2 consecutive reporting periods) • psychological wellbeing (TIM) – data completeness <p>This cleft service was also identified as a positive alert with regards to:</p> <ul style="list-style-type: none"> • psychological wellbeing – TIM scores of 1a+, seen by or having had input from a psychologist
Response
<p>None. Cleft Services identified as positive outliers / alerts were not obliged to respond to notification of their outlier / alert status.</p>

5. Trent cleft service

Notification of outlier status
<p>This cleft service was notified that they had been identified as a negative outlier with regards to:</p> <ul style="list-style-type: none"> • psychological wellbeing (TIM) – data completeness • psychological wellbeing (SDQ) – data completeness <p>This cleft service was also identified as a positive outlier with regards to:</p> <ul style="list-style-type: none"> • facial growth (5-year-index) – data completeness • speech (CAPS-A) – data completeness • speech – standard 2a, had speech without difficulties resulting from existing or previous structural anomalies* (*a positive alert for 2 consecutive reporting periods)
Response
<p>Please accept this update on the Trent Regional Cleft Network's outlier status in measures relating to Clinical Psychology in the annual CRANE Report.</p> <p>Current State</p> <p>Following delivery of the staged investment in clinical psychology agreed with Nottingham University Hospitals NHS Trust and the East Midlands Specialized Commissioners the Trent Regional Cleft Network has had in post for 12 months 1WTE Band 7 Clinical Psychologist and 0.2WTE Band 8c Clinical Psychologist. There is a further 0.6WTE Band 7 post that has been made available as agreed in the staged investment plan but no suitable applicants for the post were received after 3 rounds of recruitment so a re-banding of the post is underway with recruitment proposed in early 2024.</p> <p>Following a period scoping and set-up the Trent Regional Cleft Network clinical psychology team are now acquiring TIMs and 5 year audit data over 2023. This activity has not impacted the data performance in this report. The data in this report reflect the Trent Regional Cleft Networks performance on clinical psychological measures prior to delivery of the staged investment and recruitment plan for clinical psychology, therefore do not reflect the contemporaneous situation regarding our performance. The service expects from early internal monitoring data and activity projections to no longer be in outlier status for clinical psychology measures at the time of the next annual CRANE report.</p> <p>Action Plan</p> <p>As the full 3 year staged funding plan is delivered following re-banding and recruitment to the remaining funding for clinical psychology it is envisaged that the Trent regional Cleft Service will be able to deliver the full requirements as per Clinical Psychology in the service specification defined by D07/S/a NHS Standard Contract For Cleft Lip and/or Palate Services including Non-Cleft Velopharyngeal Dysfunction (VPD) (All Ages).</p> <p>Mr Jason Neil-Dwyer Clinical Director Trent Cleft Service</p>

6. West Midlands cleft service

Notification of outlier status
<p>This cleft service was notified that they had been identified as a negative outlier with regards to:</p> <ul style="list-style-type: none"> • consent verification • child growth (height and weight) – data completeness* (*for 2 consecutive reporting periods) • facial growth (5-year-index) – data completeness • speech – data completeness (CAPS-A) • psychological wellbeing (TIM) – data completeness • psychological wellbeing (SDQ) – data completeness* • psychological wellbeing – TIM scores of 1a+, seen by or having had input from a psychologist* <p>We also congratulated them for being identified as a positive outlier with regards to:</p> <ul style="list-style-type: none"> • dental health (dmft) – data completeness* • dental health – dmft >0 indicating experience of dental decay <p>This cleft service was also identified as a positive alert with regards to:</p> <ul style="list-style-type: none"> • dental health – dmft >5 indicating experience of extensive dental decay
Response
<p>We have identified the following causative factors:</p> <ol style="list-style-type: none"> 1. Lack of appropriate support staffing with the dedicated role in co-ordinating data collection 2. A high turnover of admin staffing period over the last 5 years due to problems with retention and appropriate banding 3. A high turnover of Cleft service managers in the last 5 years 4. Acting cleft service lead for 18 months from a non-cleft background. During this time the service was in a post-COVID recovery situation with little to no focus on data entry <p>Going forward we are trying to put additional processes in place at multiple levels to improve and maintain standards, recruit a specific data co-ordinator, and establish dedicated audit clinics. We will rely on the full support of the Trust to realise these goals</p> <p>Mr Khurram Khan Consultant Cleft, Plastic & Reconstructive Surgeon Clinical Service Lead West Midlands Regional Cleft Service</p>

7. Cleft Net East cleft service

Notification of outlier status
<p>This cleft service was notified that they had been identified as a negative outlier with regards to:</p> <ul style="list-style-type: none"> speech (CAPS-A) – data completeness* (*for 2 consecutive reporting periods) <p>Your cleft service has also been identified as a negative alert with regards to:</p> <ul style="list-style-type: none"> dental health – dmft >5 indicating experience of extensive dental decay speech – standard 1, speech with no evidence of a structurally related problem and no cleft speech characteristics requiring intervention speech – standard 3, speech without cleft-related articulation difficulties <p>We also congratulated them for being identified as a positive outlier with regards to:</p> <ul style="list-style-type: none"> child growth (height and weight) – data completeness* dental health (dmft) – data completeness psychological wellbeing (SDQ) – data completeness psychological wellbeing – TIM scores of 1a+, seen by or having had input from a psychologist** (**a positive alert for 2 consecutive reporting periods)
Response
<p>Cleft.NET.East response to identification as negative outlier for speech (CAPS-A) data completeness.</p> <p>Speech data completeness at age 5 (before they turn 6), children are seen face to face and a clinical management plan is decided. Children complete a formal speech assessment which is video recorded. The video is then re-watched at a later date by a minimum of two CAPS-A trained speech therapists who rate independently and then reach a consensus on 16 CAPS-A speech parameters. For children who are consented these are then reported to CRANE. The process of watching and rating takes between 15-30 minutes per video, depending on complexity. To have reported complete CRANE data, means videos made, watched and all 16 CAPS-A speech parameters reported for eligible children.</p> <p>This CRANE report, reports on outcomes of children born in 2014, 2015, 2016. Speech data was not complete for the following reasons;</p> <ol style="list-style-type: none"> 1) Lack of videos made to report on. COVID-19 restrictions in 2021 and 2022 resulted in virtual 5 year appointments for some patients in 2014 and 2015 birth cohorts. Whilst clinical management plans were made virtually, assessments could not be recorded which resulted in incomplete data. Now face to face appointments have been reinstated, videos are now being collected again and this has resolved. 2) Lack of CAPS-A trained listeners. The Cleft.NET.East team did not have enough trained CAPS-A listeners and there were no courses available, to report on speech outcomes from 2014 birth cohort. Therefore videos were not reported on, resulting in incomplete data. Two members of the SLT team completed CAPS-A training in October 2022 and are now reporting on collected samples. One more CAPS-A trained listener has re-joined the team, however 2 trained listeners have left, therefore leaving the team with just 2 internal listeners. It will be important to ensure more training courses are available to train more SLTs to ensure future data completeness. <p>Incomplete data by year; 2016 birth cohort: Full speech data reported for 30/39. No speech data reported for 9/39. 6 clinically contraindicated. 2 Did not attend/Cancelled. 1 unable to rate poor video quality.</p> <p>2015 birth cohort: Full speech data reported for 7/39. No speech data reported for 32/39. 26 were not seen face to face so not collected due to Covid-19. 5 were clinically contraindicated. 1 Did not attend/Cancelled.</p> <p>2014 Birth cohort: Full speech data reported for 0. No speech data reported for 52/52. 26 had videos but were not CAPS-A reported due to lack of listeners. 26 were not seen face to face due to Covid-19, so no video collected. 1 was clinically contraindicated.</p> <p>Summary we have addressed these issues by restarting face to face appointments where videos are made. We have enrolled more SLTs in CAPS-A training and will be requesting to enrol another SLT as soon as this is available. We have expedited and completed listening of all available videos which means we will be able to report on all available data for 2023 report (2015,2016,2017 birth cohorts).</p> <p>Cleft.NET.East response to identification as negative alert for speech Standard 1, speech with no evidence of a structurally related problem and no cleft speech characteristics requiring intervention and Standard 3, speech without cleft-related articulation difficulties.</p>

Speech standard 1. This is the achievement of speech with no evidence of a structurally related problem and no cleft speech characteristics requiring intervention (green) ratings across all 16 CAPS-A speech parameters, therefore related to both articulation and structural outcomes.

Speech standard 3. This is the achieved in cases where patients have normal (green) ratings across articulation outcomes, with no anterior Oral CSCs, Posterior Oral CSCs, Non Oral CSCs or gliding of fricatives (a Passive CSC).

This CRANE report, reports on outcomes of children born in 2014, 2015, 2016. Speech data over this period of time was not complete for the reasons described in 'Cleft.NET.East response to identification as negative outlier for Speech (CAPS-A) data completeness'. Therefore data for this alert is based on just one year's full data (2016).

We have addressed these alerts by:

- Expediting listening of all available videos and looking in detail at all cases who did not meet 'good' standard, to understand reasons for this.
- Prioritising face to face speech assessments at age 3 to allow identification of speech difficulties, enabling timely referral for intervention if required, aiming to resolve errors before age 5.
- Increasing our early speech therapy input from 18months-3years, aiming to reduce number of Cleft type articulation difficulties developing in younger children.
- Finally, initiating discussion with the Community SLT Managers across the region, regarding access to effective and equitable speech therapy intervention.

Summary we have addressed this alert, by exploring reasons for less satisfactory outcomes and addressing these with changes to our pathway of care, and our speech therapy intervention offers. We have expedited listening of all available videos which means we will be able to report on all available data for 2023 report (2015,2016,2017 birth cohorts).

Dental Response to Negative alert

1. 1. During the time these children were born to age 5, Dental shortage of staff only 4 sessions per week instead of 8, so unable to see all children, so focused/prioritised those with known disease. (Currently have a post available with increased sessions, so this should help to improve the number of patients seen going forward).
2. Not reported here but in main body of report- treatment index which is a measure of treated dental disease, is high in our cohort as we address it when identified - when we treat, we use x-rays and pick up all caries, not just visible caries (the dmft score is based on visually identifiable caries). So our use of x-ray detection increases the numbers of children treated, as it includes those with unseen dental cares, in addition to those visible caries, thus increasing our dmft score.
3. Data from some other centres is collected by non-paediatric dentists and non-calibrated dentists, so not comparable, but none-the-less included.
4. We have several areas of high deprivation and high caries levels generally in children in our region e.g. Luton, Peterborough and Great Yarmouth
5. "The Covid effect" particularly 2016 births mean many have not seen a dentist for at least 2 years - East of England has been highlighted nationally, as an area with an acute shortage of NHS dentists. (We rely on local dentists for preventive treatments and to pick up disease early). Many families are struggling access local dentists, and not all local dentist accept children who required dental treatment associated with Cleft.

N.B. We would like to acknowledge the huge work and effort given by our SLT team who have worked very hard to improve our speech outcomes over a 6 month period, since completing the CAPS A training, and their continuing efforts to do so, improving data completeness for those years where data is missing.

We would like to acknowledge our Clinical Psychology team for their efforts in maintaining their positive Outlier status. This should be acknowledged given staffing issues and their inability to participate in the MDT clinic. A temporary step back from the MDT clinic has allowed the team to focus on providing individual patients, bespoke support.

We would also like to acknowledge our Clinical Nurse Specialists and Admin teams, including our new Data Manager, in facilitating and supporting robust systems with the support of the MDT, in collect missing consents and identifying unknown crane status. Consents for New babies, with the completion of Data sheets has increased the numbers of Consents received.

We have initiated processes, in clinic settings for checking and verifying consents with parents. We note that prior to the deadline, we were expected to be Negative outliers for our Consent. By implementing these new processes for collecting consent and data, we have been able to vastly improve our status and avoid negative outlier status for this standard. We are currently working on collecting missing consents for 2017 and 2018 to ensure that data collected in respect of individual specialities, can be added to the data base.

Peri Codling
Clinical Lead, **Cleft Net East**

8. North Thames cleft service

Notification of outlier status
<p>This cleft service was notified that they had been identified as a negative outlier with regards to:</p> <ul style="list-style-type: none"> dental health (dmft) – data completeness* (*for 2 consecutive reporting periods) speech – standard 2a, had speech without difficulties resulting from existing or previous structural anomalies psychological wellbeing – TIM scores of 1a+, seen by or having had input from a psychologist* <p>This cleft service was also identified as a negative alert with regards to:</p> <ul style="list-style-type: none"> speech – standard 1, speech with no evidence of a structurally related problem and no cleft speech characteristics requiring intervention <p>We also congratulated them for being identified as a positive outlier with regards to:</p> <ul style="list-style-type: none"> child growth (height and weight) – data completeness psychological wellbeing (TIM) – data completeness <p>This cleft service was also identified as a positive alert with regards to:</p> <ul style="list-style-type: none"> consent verification
Response

The North Thames Cleft Team response to the CRANE notification of outlier status for cleft outcomes recorded on CRANE.

As a team we recognise the importance of reporting on clinical outcomes as a means of driving improvements for the patients that we look after. As such we acknowledge the importance of this process and the ultimate aims of its directive.

Having received this notification [redacted], I contacted the relevant stakeholders in psychology, SLT and paediatric Dental specialities (those appearing as negative outliers), along with the data coordinators from both of our twin site centre, to discuss the submitted data and the factors contributing to a negative outcome status. Previously, changes in staff had made identifying the relevant patients on the crane database difficult. However, our data coordinators are now much more familiar with the CRANE database workings and were able to provide the cohort of patients much sooner. Following this, the individual specialities were able to meet separately, in order to analyse their data more fully and provide feedback to the team on the potential reasons for these negative outcomes.

Psychology Outcomes

Following the 2014-2016 CRANE report, our psychology colleagues have reviewed the psychology data to look into why we are a negative outlier for those given a TIM (tier) score of 1a+ at the 5 year audit. All the data on CRANE is correct, in line with the data we have, so nothing needed to be modified.

Below is a detailed summary of all those patients with outcomes, registered on CRANE born between 2014-16 inclusive:

	2014		2015		2016	
	GOSH	CHELMS	GOSH	CHELMS	GOSH	CHELMS
Total patients (consented)	86	45	74	36	81	36
TIM 1a	16	11	10	2	46	6
TIM 2+	34	18	15	19	4	17
% total TIM 1a+	58%	64%	34%	58%	62%	64%

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TIM 0	11 4 = 0c, staff sickness 7 = 0d, lack of staff resource during vacancy gap	1 1 = 0e (psych declined by patient)	18 18 = 0d, lack of staff resource	0	9 9 = 0d, lack of staff resource	4 1 = 0b, psych on AL 2 = 0c, staff sickness 1 = 0e, psych declined by patient
TIM missing with reason code	25 10 = Patient DNA/cancelled 14 = other (no cleft MDT clinic logged, or patient not known) 1 = deceased	15 6 = <u>clinic cancelled</u> due to covid-19 1 = not suitable for audit 5 = DNA suspected due to Covid-19 3 = transferred out of area	31 All of these were due to not being seen at MDT, likely due to COVID (clinic would be 2020/2021)	15 8 = DNA suspected due to COVID-19 3 = transferred in or out of area 1 = deceased 1 = lack of staff/facilities 2 = other	22 12 = patient DNA/cancelled 3 = other (not invited to audit, no longer known to GOSH) 5 = transferred in or out of area 1 = deceased 1 = not seen at birth or at 5 years	9 3 = DNA 1 = transferred in or out of area 5 = other (not seen prior to 6 th birthday) – possibly due to COVID?

358 patients consented to CRANE between 2014-2016 at GOSH and Broomfield. The total number of patients given a TIM score, and therefore included in the analysis is **241**.

Total 1a+ = 198 (82%)

18% (n = 43) of patients seen by psychology were given TIM scores of less than 1a+

- 2% of these patients weren't seen due to psychologist being on AL (0b)
- 14% of these patients weren't seen due to staff sickness (0c)
- 79% of these patients weren't seen due to lack of staff resource (0d) – all from GOSH. This may be due to a gap in staff recruitment or limited availability of staff attending clinic due to COVID.
- 5% of these patients weren't seen as psychology was declined by patient (0e)

It is worth mentioning that 117 of the patients registered with CRANE were not given a TIM score at all. The most common reason for this is the COVID-19 pandemic and its affects (clinic cancelled, DNA suspected due to COVID-19). Other reasons include, transferred in or out of area, deceased, not seen prior to 6th birthday, not suitable for audit, and other.

In Conclusion

1. It appears the greatest contributor to the 1a+ TIM score from the Great Ormond Street Hospital site is due to staff absence within the 5-year audit clinic.
2. 117 patients registered with crane were not given a TIM score at all. This is predominantly due to the significant impact of COVID-19 on attendance at our audit clinics.

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Recommendations

- The psychology service has made some administrative changes so that there are now clear systems in place to monitor attendance at the 5-year audit clinic and to ensure timely liaison with the Team to review re-booking cancellations/DNA's.
- Psychology now aims to improve flexibility across the psychology service so that the 5-year audit clinic is covered in the event of staff absence. This also highlights difficulties with recruitment within the NHS and the impact of the 3-month notice period.
- Psychology provision generally within the cleft service needs to be reviewed in light of these findings. The overall level of psychology provision within the cleft service was reduced some 3-4 years ago, following a review, by GOSH trust, into psychology service provision generally throughout the trust.

Speech and Language Therapy - Speech – 2a outcomes

The North Thames Cleft Service has been identified as a negative outlier with regards to Speech – Standard 2a (speech with no evidence of a structurally related problem and no history of VP surgery or fistula repair for speech). We have been identified as a negative alert with regards to Speech – Standard 1 (speech with no evidence of a structurally related problem and no cleft speech characteristics requiring intervention). Standard 3 (no cleft type articulation difficulties which require therapy or surgery) was met by the service. Standard 1 reflects speech as a whole and is therefore directly influenced by standards 2 and 3. As standard 3 was met by our service, our conclusion is that standard 1 has been negatively influenced by the outcomes for standard 2a in the time periods being considered.

Considerations of the patient cohort:

- 2014 – Majority of patients were operated on by one surgeon. Over this period records suggest that biomaterials were employed to aid surgical closure. This may be implicated in these outcomes but until we have a more thorough review of this entire cohort the potential adverse effects of biomaterial use are inconclusive.
- 2015 – the number of patients who had audio-visual recordings and were therefore eligible for consensus listening was *extremely* low due to Covid. As such it is difficult to draw any conclusions from this data.
- 2016 – Again, the majority of patients were operated on by one surgeon again due to surgical team sick leave.

Plans to review the data and reflect on why Standard 2a falls so far below the set threshold include the following:

- To review the entire cohort for the years above and include clinical data for patients who were excluded due to audio-visual recordings not being available or who did not attend for audit (we have clinical information on them from another clinic) or where there were technical issues on the day of audit.
- Analyse the data to determine if there are any issues relating to:
 - Surgical protocols including use of biomaterials and timing of palate repair
 - Patient specific factors including width and extent of cleft o Intraoperative issues or comments including asymmetry of palate
 - Surgeon specific outcome data to identify any differences in technique
 - To compare outcomes to data from previous years, where our outcomes have been significantly better

The data will be shared with both the surgeons individually and with the team, to allow for comment and reflection.

Following this audit exercise, should any specific factors be identified which are implicated in producing poor outcomes, then these will be discussed with the team and the necessary changes to protocol implemented.

Plans to improve data completeness:

Despite not being an outlier for completeness, as a service we are not as “complete” as we would like to be. SLT data completeness is impacted by service-wide data input issues.

We have made the following plans to improve the service's data completeness figures for 2024:

- Improve adding clinical diagnoses (including LAHSHAL codes) to our EPR system as syndromic diagnoses can evolve over time. We plan for the age 3 MDT appointment to be a good time to review all patient's diagnoses and amend on our EPR system and alert our data coordinators that there are updates for CRANE.
- Ensure patient lists downloaded from CRANE are truly reflective of our patient cohort and remove any who have been entered incorrectly.
- Review the 2015 and 2016 data completeness and amend as needed.

Paediatric Dentistry 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 have always had one calibrated clinician in the team but, as a result of these untimely circumstances, it meant that our paediatric dental consultant provision was effectively reduced by two thirds. This left the remaining consultant covering the needs of all the paediatric dental service for the hospital. Since January of 2023, the only calibrated consultant paediatric dentist in the department has been on long-term sick leave.

On a significantly more positive note, we have now appointed a new Consultant paediatric dentist with a specific requirement to cover our cleft audit clinics. The incoming consultant has contacted the paediatric dental CEN and is due to be calibrated in December of this year. In addition, one of our hospital doctor grade paediatric dentists will be attending this training also. This will mean that we will then have two calibrated clinicians working in the department. In addition, we intend to appoint a further substantive consultant paediatric dentist and intend for them to be similarly calibrated. With the anticipated return of our consultant currently away on long-term sick leave, this will significantly improve flexibility and resilience to record this data for the cleft team.

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.

In Summary

1. With regard to psychology, it appears that a combination of psychology resource and the impact of the effects of Covid19 have contributed to our outlier status in relation to our comparatively low TIM 1a+ scores. We intend to review the psychology service provision for the cleft team to see whether increased resource can be secured, to mitigate the impacts on staff absence at cleft audit clinics.
2. With regard to the speech and language therapy outcome 2 a, this has identified surgery as being the main factor affecting this structural and functional SLT outcome measure. From a review of the patient cohort for each of the 3 years, we have identified some factors which may have contributed to this. However, given the complexity and multifactorial nature of the factors involved which may have led to these poorer outcomes, we are currently engaged in an in-depth audit of all those patients identified, to examine all the factors which could have contributed to this outcome, with the aim of identifying more accurately, the potential causes. The intention is to share this information with our surgeons and any learning that may come from this exercise, to be implemented in improving the speech outcomes for our patients.
3. The appointment of additional calibrated paediatric Dentists to the cleft team has been our priority and we have now achieved this, with our incoming substantive consultant paediatric dentist, job planned to attend our cleft audit clinics and lead on data submissions. This consultant, along with one of our paediatric dental hospital doctors, will be completing the training this December, which will address our reporting of paediatric dental outcomes. The appointment of a second substantive consultant to the remaining PAs available, along with the return of our consultant on long-term sick leave, will significantly improve resilience within the cleft team and address the problem of paediatric dental data collection.

We have had some time to reflect as a team on how we might improve our processes moving forwards and have listed these in the recommendations above. We feel the speech outcome requires an in-depth analysis of the patient related clinical data along with a review of our surgical protocols and the psychology outcome requires a review of the available clinical resource. We feel we have systems in place to address the paediatric dental situation. We would of course appreciate any further advice from the CDG Quality Monitoring & Improvement Committee if this is deemed helpful.

Mr Norman Hay
Clinical Director North Thames Cleft Lip and Palate Team
North Thames Cleft Service

9. The Spires cleft service

Notification of outlier status
<p>This cleft service was notified that they had been identified as a negative outlier with regards to:</p> <ul style="list-style-type: none"> child growth (height and weight) – data completeness <p>This cleft service was also identified as a negative alert with regards to:</p> <ul style="list-style-type: none"> consent verification <p>We also congratulated them for being identified as a positive outlier with regards to:</p> <ul style="list-style-type: none"> dental health (dmft) – data completeness* (*for 2 consecutive reporting periods) psychological wellbeing (TIM) – data completeness psychological wellbeing (SDQ) – data completeness dental health – dmft >0 indicating experience of dental decay** (**an alert for 2 consecutive reporting periods) psychological wellbeing – TIM scores of 1a+, seen by or having had input from a psychologist <p>This cleft service was also identified as a positive alert with regards to:</p> <ul style="list-style-type: none"> dental health – dmft >5 indicating experience of extensive dental decay
Response
<p>Negative outlier: child growth (height & weight): This data is largely collected by Play Specialists at the Clinical Review Clinics.</p> <p>Personnel changes have meant that there has been a period when we have been unable to collect this data; this has now been rectified and we are therefore confident that going forward we should have no further issues in data collection. Furthermore our audit proformas now include a compulsory section whereby this data must be recorded thus acting as an essential aide memoire on the day.</p> <p>Negative alert: consent verification: Our consent verification process has been tightened up such that we intend to ask families on three separate occasions in order to ‘capture’ as many families as we can:</p> <ol style="list-style-type: none"> At first CNS review (although this juncture is not appropriate for many families). At first cleft clinic review with cleft surgeon (when the majority are now verified). A ‘backstop’ check for consent verification will be made at our Toddler Clinic at the age of approximately 20-22 months. <p>The clinical notes (paper and electronic) are ‘marked’ with the CRANE consent status such that those who have yet to be asked are not missed at a subsequent clinical encounter.</p> <p>Those families who refuse consent at any stage (a rare situation in our experience) would not be approached again.</p> <p>Positive outlier (dmft completeness) and positive alert (dmft >5): Our dental team - Giles Kidner (Orthodontics), Mary Bussell (Orthodontics), Helen Travess (Orthodontics) and Sandip Popat (Restorative Dental) – ensure that dmfts are completed for all children at our Clinical Review Clinics across the Spires network.</p> <p>As far as dental health is concerned we looked at the ‘dental desert’ issue as part of our forthcoming Tricentre (Treble Cleft) Audit on the 10th November. Perhaps surprisingly, fewer than 5% of our families struggled to register with a GDP. Possibly this, combined with the relative affluence of much of the Spires patch (accepting that we have pockets of significant deprivation including Slough, Swindon and Portsmouth for example) coupled with the involvement of a Dental Educator in our Toddler Clinics with reinforcement about the importance of maintaining optimal dental health at every clinic visit may explain this positive alert status.</p> <p>Of concern, I note a footer on the Calibration Certificate that Helen Travess received earlier this year following her successful dmft calibration (see attached document). It states that “Successful calibration enables you to collect data but only data collected by a Specialist or Consultant Paediatric Dentist is eligible for submission to the dashboard”. I would appreciate clarification on where we stand with this statement as, in a stroke, we will be</p>

transformed for a positive outlier to a negative outlier without sound reason. We have been making significant efforts to appoint a Paediatric Dentist – indeed we are hopeful of making headway in the future – but at present we are dependent on our highly experienced Consultant Orthodontic and Consultant Restorative colleagues (all of whom are dentally qualified!). To suggest that they are capable of collecting data yet are not then able to utilise this data seems nonsensical and a waste of resource – especially the time and willingness of our patients! Such a statement as expressed on this certificate is surely open to challenge on the grounds of common sense and the fact that it seems unethical to collect data and then allow it to lie fallow and not utilise it for the common good.

Positive outlier: TIM, SDQ & TIM Scores

In the past Spires were struggling with Clinical Psychology provision due to a vacant position in Salisbury. We are now in the fortunate position where all of our clinical psychology posts are filled (albeit one of our team are currently on maternity leave) with further support from clinical assistants at both sites. Thus our Clinical Psychology team are now able to offer an excellent service and therefore in terms of data completeness and psychological input we are in an extremely fortunate position.

Mr Marc Swan
Clinical Lead/Director
Spires Cleft Service

10. South Wales cleft service

Notification of outlier status
<p>This cleft service was congratulated for being identified as a positive outlier with regards to:</p> <ul style="list-style-type: none"> • child growth (height and weight) – data completeness* (*for 2 consecutive reporting periods) • dental health (dmft) – data completeness* • speech (CAPS-A) – data completeness • psychological wellbeing (TIM) – data completeness • psychological wellbeing (SDQ) – data completeness*
Response
<p>I have discussed this with staff and we have highlighted reasons below for why we have been successful in completing the data for these categories.</p> <ul style="list-style-type: none"> • Good administration support; the admin team go to such great efforts to ensure all the 5 year olds are seen in clinic before they are 6 years of age. Our admin staff chase patients, so they attend. • We also have a clear Was Not Brought policy which helps patients to attend for MDT appointments. • We have designated 5-year and 10 year old audit clinics. Having designated clinics allows staff to remember everything we need to collect and record. • A Clinical Psychologist (CP) and an Assistant Psychologist (AP) attend our clinics. They can ask patients to complete their SDQ if they have forgotten it, early in the clinic by the CP and then follow up or collect it in at the end of the clinic by the AP. • We have implemented a proforma at the designated 5 year old clinics. This has enabled us to record dental results and growth directly onto the proforma at the time of the clinic rather than searching through the medical note entries at a later date. If we are unable to obtain the information, a reason is given at the time. • We have the same dental nurse who takes height and weight measurements. This is a routine part of the appointment. • The cleft secretary inputs the information onto CRANE when she is typing the clinic letters, inputting clinic by clinic. This makes it a manageable task which 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 also go back to look at any missing data and the explanations for this. • Those identified to input information have received training from CRANE staff, which has been very helpful and they also have contact numbers to contact CRANE staff should difficulties arise. They have both attending the “Making it Better” sessions. • Many MDT staff have been committed to not taking leave when there are 5 year clinics, this has facilitated all patients being appointed in the required time frame. • In conclusion, data completeness has been an all-round team effort! <p>Helen Extence Clinical Director The Welsh Centre for Cleft Lip & Palate South Wales Cleft Service</p>

11. South West cleft service

Notification of outlier status
<p>This cleft service was notified that they had been identified as a negative outlier with regards to:</p> <ul style="list-style-type: none"> • child growth (height and weight) – data completeness* (*for 2 consecutive reporting periods) • dental health (dmft) – data completeness* • facial growth (5-year-index) – data completeness* • speech (CAPS-A) – data completeness • psychological wellbeing (TIM) – data completeness • psychological wellbeing (SDQ) – data completeness
Response
<p>Thank you for your recent letter regarding the response from the South West cleft service about negative outliers status. We are aware that we have been identified as a negative outlier with regard to:</p> <ul style="list-style-type: none"> • Child growth (height and weight) – data completeness for 2 consecutive reporting periods. • Dental health dmft – data completeness. • Facial growth 5 year index – data completeness. • Speech (CAPS–A) – data completeness. • Psychological wellbeing (TIM) – data completeness]. • Psychological wellbeing (SDQ) – data completeness. <p>The difficulties with service provision provided by the South West Cleft Service is well documented through the cleft development group reports and discussion. Deficits in provision for our service meant that we were in a difficult position going into the pandemic response period, and failing in areas during the pandemic recovery. Engagement of the trust with NHS England specialist commissioners in an open conversation have become a regular commitment. The trust has responded very positively to outcome recommendations from a recent thematic review of the service.</p> <p>Underlying the outlier status for all points listed above is the need for expansion of staff members in most member specialities at the cleft MDT, for which a business case has been accepted. Adequate facilities for outpatient appointments to undertake audit clinics has been proposed and plans are underway for a cleft department.</p> <p>We have begun regular 5 and 10 year audit clinics again in the Bristol centre and are planning adequate regional clinic increases to collect the same data.</p> <p>I hope this reassures our expectations and plans for recovery in these outlying areas.</p> <p>Mr Alistair Cobb Consultant Cleft and Maxillofacial Surgeon Clinical Director South West Cleft Service</p>

12. Evelina London cleft service

Notification of outlier status
<p>This cleft service was notified that they had been identified as a negative outlier with regards to:</p> <ul style="list-style-type: none"> • child growth (height and weight) – data completeness* (*for 2 consecutive reporting periods) • dental health (dmft) – data completeness* • speech (CAPS-A) – data completeness • speech – standard 2a, had speech without difficulties resulting from existing or previous structural anomalies** (**a negative alert for 2 consecutive reporting periods) <p>This cleft service was also identified as a negative alert with regards to:</p> <ul style="list-style-type: none"> • psychological wellbeing (SDQ) – data completeness
Response
<p><u>Data Completeness</u></p> <p>You have identified that the Evelina London Cleft Service appears as a negative outlier or alert for a number of areas – most of which relate to our ‘data completeness’. We were negative outliers for three aspects:</p> <ul style="list-style-type: none"> • child growth (height and weight) – data completeness • dental health (dmft) – data completeness • speech (CAPS-A) – data completeness <p>And a negative alert for another:</p> <ul style="list-style-type: none"> • psychological wellbeing (SDQ) – data completeness <p>Our main issue for this year’s report has thus been with regard to the data collection process – something that we have struggled with for some time now but which we are working hard to resolve. As you know, the patient cohort that is sampled includes three consecutive birth years (this time 2014, 2015 and 2016) and so it will take some time before our actions to improve data collection will be seen in our data completeness figures.</p> <p>Our Lead Speech Therapist has identified that for children born in 2014, 25% of eligible patients for speech audit not appointed for their 5-year audit by the service. For children born in 2015, 39% of eligible patients for speech audit were not appointed for their 5-year audit by the service. For children born in 2016, 47% of eligible patients for speech audit were not appointed for their 5-year audit by the service. This is very low indeed and we are disappointed that we have only managed to audit between 53% and 75% of children (certainly for speech) in these years.</p> <p>It seems that, in previous years, when we had regular audit clinics for our 5-year-old patients with UCLP and BCLP and when there was no backlog of patients waiting for follow-up review in the MDT cleft clinics, our 5 year olds were naturally been seen within the audit window. However, during the Covid-19 pandemic, we ceased to run formal audit clinics and we developed long backlogs for all patients to be seen in regular MDT clinics. As you can see, it was the children born in 2015 (turning 5 in 2020) and the children born in 2016 (turning 5 in 2021) who were most affected by this. With hindsight, we can now understand how so many 5-year olds missed being appointed for audit review as the regular processes were disrupted and we failed to change our systems to prioritise this cohort being expedited for clinic appointments before they turned 6.</p> <p>We now have a much more robust system in 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. I meet regularly with our Audit and Information Officer who reports back on which children have been appointed. We are hopeful that almost all children born in 2017 onwards will be appointed to appropriate clinics and 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.</p> <p>We have also put some measures in place to expedite the collecting of height and weight data at 5 years (and other required timepoints) including setting up a system whereby the dental nurses facilitating our MDT clinics routinely now weigh and measure all children who attend. And in our outreach locations, we have been able to ask the local teams to undertake this task for us. We have even bought scales suitable for babies and older children and had these delivered to some outreach centres for the cleft service to use for our clinics there.</p>

We have additional sessions of Consultant Paediatric Dental time in our service and hope that, as our newest team member is calibrated to collect audit measurements, our data completeness for DMFT will also improve.

Speech – Standard 2a

“The achievement of speech without evidence of a structurally related speech difficulty.” This standard is achieved in cases where patients have no reported history of velopharyngeal surgery or fistula repair for speech purposes and have green ratings across the following six CAPS-A speech parameters: Hypernasal resonance, both nasal airflow parameters (audible nasal emission and nasal turbulence), and all three Passive CSCs.”

CRANE have identified the Evelina London Cleft Service as being a negative alert with regards to this standard.

Our Lead Speech and Language Therapist explains that, whilst the speech outcome data submitted to Crane for the birth years 2014 – 2016 is accurate and has been consensus listened to by three CAPS-A trained listeners (with an external listener present for the first 10 patients born in every year group who also have a 5 year audit available), the speech outcome data submitted is likely not representative of our total patients eligible for audit for the birth years 2014 to 2016. This is felt to be due to two issues:

1. General **data incompleteness** for the birth years 2014, 2015 and 2016. As has already been discussed above, the service only managed to appoint a reduced subset of patients eligible for a speech recording and audit to be carried out at age 5 years
2. For the birth year 2015 (children who turned 5 in 2020), the number of patients seen face to face was negatively affected by COVID 19. Many patients were seen virtually in this period and **speech recordings could not be carried out in virtual 5-year reviews**. A consensus listen cannot be carried out without a speech recording. So, for the birth year 2015, only 22/88 of the total eligible patients for speech audit were audited - this amounts to only 25% of the total number of eligible patients for speech audit for the year 2015 and is therefore not a representative sample to draw reliable or valid conclusions from in terms of outcome reporting.

Consent

We are delighted that the processes that we put in place following the 2022 CRANE report have paid off and that we are no longer an outlier for consent verification. We continue to work on this and regularly interrogate CRANE to see where consent is missing for children born in the current birth year cohort (and previous years) and contact families to collect this retrospectively as much as possible – seizing every opportunity to speak with families who come to appointments and proactively contacting others in order to explain the importance of CRANE and to sensitively seek their consent to register their children. Consent verification is now firmly built into the existing Cleft Clinical Nurse Specialist pathway with a goal of all relevant patients having had consent established (through contact with parents) within the first 6 months of life, and certainly by 12 months.

Conclusion and Plans for the Future

Similarly, to last year, we are reassured that the areas where we remain outliers in this year’s report represent a historical struggle to complete all checks at pre-defined time points (considered appropriate in the patient journey). The main areas where we are outliers refer to aspects which are measures of our processes and thus our data completeness. We are only a negative ‘alert’ for one outcome measure (a subsection of the speech standards measures). The 2023 CRANE report does not appear to be suggesting that our patient group are receiving inadequate clinical care or poorer outcomes – the data show that this clearly is not the case.

We have put a number of measures into place to ensure that the Evelina London Cleft Service moves out of outlier status as quickly as possible. These include:

- Regular meetings between the Audit and Information Officer and the Head of Service to review processes and to ensure that all children are booked an appointment in an audit or MDT clinic in the year whilst they are 5.
- Constant checking and cross-referencing with the CRANE database to see where there are gaps in our consent verification or data entry. Informing the lead clinicians whenever it is identified that a child has consent on CRANE but where there is no clinical data yet uploaded. Ensuring that the CRANE database is as complete and up to date as possible.
- Provision of equipment to outreach centres to support audit data collection (especially height and weight) and a more robust system for collecting and reporting this.
- Working towards getting an additional Consultant Paediatric Dentist calibrated to be able to report DMFT scores
- Adding the situation with our 5-year audits (and the service’s failure to appoint sufficient children to clinics before they turned 6) to our NHS Trust’s Risk Register. This is a management tool that provides a repository

for risk information across all areas of activity. It allows the NHS Trust to monitor our development in this area, to set targets for improvement and to oversee the progress we make.

It will take some time before the work that we are doing will filter through into the CRANE report as the birth year cohort only changes by one year out of the three for each CRANE report.

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 know that the intention is to help us to continue to work for patient benefit and to ensure that our cohort of individuals born with a cleft receive excellent care. We remain fully committed to this process and this report has been shared with the clinical leads within our team and also with the Clinical Director for the Children's Surgery Theatres and Anaesthesia (CSTA) Directorate within Evelina London.

Overall, we are pleased to see how well Evelina compares to the other 12 regional services in terms of the quality of our outcomes. On the whole we compare very favourably to the other national services and I am proud of the team and the work of the Evelina London Cleft Service. 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																																							
<p>This cleft service was notified that they had been identified as a negative alert with regards to:</p> <ul style="list-style-type: none"> facial growth – 'good' 5-year-index scores <p>We also congratulated them for being identified as a positive outlier with regards to:</p> <ul style="list-style-type: none"> dental health (dmft) – data completeness* (*for 2 consecutive reporting periods) <p>This cleft service was also identified as a positive alert with regards to:</p> <ul style="list-style-type: none"> psychological wellbeing (SDQ) – data completeness 																																							
Response																																							
<p>Positive Outlier - dental health (dmft) – data completeness</p> <p>For both 2022 and 2023 reports data completeness for dental health has been 100% with data completeness for 2021 report 97%.</p> <p>All children born in NI are added to a spreadsheet and the following information is captured: cleft type; syndrome; date of clinic; attend/ DNA/ CNA; transfer; dmft; photos /imps taken; next clinic. This information is then transferred to CRANE by both the Cleft Coordinator and Dentist, followed by cross checking to ensure no data is missing.</p> <p>Positive Outlier - psychological wellbeing (SDQ) – data completeness</p> <p>Psychology assistant uploads data to CRANE following every clinic. Cleft coordinator and Cleft Psychologist meet to cross check all data on CRANE and check for any missing data and ensure all cases are accounted for including transfers, FTA etc.</p> <p>Negative Alert - facial growth – 'good' 5-year-index scores</p> <p>The 2019 CRANE report looked at outcomes for 5 year olds (born between 2004 and 2012) with poor facial growth scores according to the number of children at each region/ unit with index scores and NI achieved an average score as shown below:</p>																																							
<p>Figure 7.1. Funnel plot of 5-year olds (born between 2004 and 2012) with poor Five Year Old Index scores according to the number of children at each region / unit with index scores.</p> <table border="1"> <caption>Approximate data points from Figure 7.1</caption> <thead> <tr> <th>Region / Unit</th> <th>Number of cases with five year old index scores</th> <th>% cases with poor scores</th> </tr> </thead> <tbody> <tr><td>Swansea</td><td>15</td><td>38</td></tr> <tr><td>Northern Ireland</td><td>25</td><td>28</td></tr> <tr><td>Bristol</td><td>50</td><td>38</td></tr> <tr><td>Liverpool</td><td>65</td><td>32</td></tr> <tr><td>Newcastle</td><td>70</td><td>30</td></tr> <tr><td>Leeds</td><td>75</td><td>18</td></tr> <tr><td>North-Thames</td><td>80</td><td>15</td></tr> <tr><td>Trent</td><td>85</td><td>25</td></tr> <tr><td>Manchester</td><td>90</td><td>30</td></tr> <tr><td>West Midlands</td><td>110</td><td>28</td></tr> <tr><td>Spire</td><td>125</td><td>28</td></tr> <tr><td>South Thames</td><td>135</td><td>22</td></tr> </tbody> </table>	Region / Unit	Number of cases with five year old index scores	% cases with poor scores	Swansea	15	38	Northern Ireland	25	28	Bristol	50	38	Liverpool	65	32	Newcastle	70	30	Leeds	75	18	North-Thames	80	15	Trent	85	25	Manchester	90	30	West Midlands	110	28	Spire	125	28	South Thames	135	22
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<p>Mr Chris Hill Clinical Lead/Director Northern Ireland Cleft Service</p>																																							