Promoting excellence in cleft care

Cleft Registry and Audit NEtwork Database

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

2025 Annual Report

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

On behalf of the Cleft Development Group

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Commissioned by the National Specialised Commissioning Group for England, the Welsh Health Specialised Service (WHSSC), the Northern Ireland Specialist Services Commissioning Team, and Cleft Surgical Service for Scotland

This version (1.1) was released on 31 December 2025 and includes corrections to: (a) percentage of registrations that were girls (page 5), (b) percentage of children with ‘good’, ‘fair’ and ‘poor’ dental arch relationships (page 7), and (c) number of children eligible for CAPS-A assessment (page 46).
Version 1.0 was released on 08 December 2025

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CLAPA
Cleft Lip & Palate Association

The Cleft Lip and Palate Association (CLAPA) is a small charity working to improve the lives of people born with a cleft and their families in the UK. We tackle isolation by connecting the cleft community and provide personal support and accessible information at all stages of the cleft journey. We empower parents and patients to have an impact on cleft care through participation in research, and act as the leading voice of people affected by cleft in the UK. Our vision is a society where everyone affected by cleft feels informed, connected, reassured and empowered. Visit www.clapa.com to find out more.

Registered charity no: 1108160 (England & Wales) & SC041034 (Scotland)

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Documents related to this product, for reference, published separately	**Published**
2025 Annual Report: The supplementary tables (Appendices) (Excel Workbook)	December 2025
2025 Annual Report: Responses to outlier process (Appendices)	December 2025

Acknowledgements

We gratefully acknowledge:

- The children born with a cleft, their families, and the Cleft Services across England, Wales, Northern Ireland, and Scotland for submitting data to the CRANE (Cleft Registry & Audit NEtwork) Database.
- Members of the UK NHS Cleft Development Group (CDG), chaired by Ginette Phippen, for their advice.
- Members of the Quality Improvement and Monitoring Committee (QMIC), chaired by David Sainsbury, for their support given during the outlier process to Cleft Services identified as outliers.
- Heather Sahunta, representing the Nursing Clinical Excellence Network (CEN), for reviewing the registry, consent, and child growth chapters.
- Joanna May, on behalf of the Dental CEN, for reviewing the dental chapter.
- Ailbhe McMullin and Rachael Willis, on behalf of the Orthodontic CEN, for reviewing the facial growth chapter.
- Lorraine Britton and Imogen Underwood, representing the Lead Speech and Language Therapy group and CEN, for reviewing the speech chapter.
- Jen Rundle, on behalf of the Psychology CEN, for reviewing the psychology chapter.
- Catherine de Blacam for providing medical illustrations of different cleft phenotypes.

We would like to acknowledge all Cleft Services for supporting the outlier process, which was formally implemented this year. We recognise the extra time and effort it has taken for clinical colleagues to engage and respond so constructively to outlier communications. The positive way in which the outlier process has been received and responded to is hugely encouraging for the future of national clinical audit of cleft care. The process was adopted by the CDG in 2022 and was introduced in a staged manner in 2023 to allow all teams the necessary time to put in place appropriate resources. The staged implementation also reflects the significant ongoing pressures experienced by clinical services during recovery from the various waves of the COVID-19 pandemic. From this year onwards, the outlier policy will be implemented in full.

The work involved in producing this report was funded by the Specialised Services National Business Intelligence and Information Team NHS England and NHS Improvement on behalf of England and Wales, the Northern Ireland Specialist Services Commissioning Team and Cleft Surgical Service for Scotland. It was conducted by the project team of the CRANE Database, which is overseen by the UK NHS CDG[1].

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[1] **The supplementary tables** provide detail on the project team, and the project's governance and funding arrangements. The Cleft Development Group CRANE web page provides detail on the CDG Membership and Terms of Reference.

Foreword

I am both relieved and delighted to be able to invite you to read the 2025 CRANE report. Relieved, because this time last year there was a significant threat to the future of our UK-wide registry and audit database. Delighted, because CRANE continues, albeit with a fragile level of security. Last year I urged Cleft Services and clinical specialties to recognise the value of CRANE and support its ongoing work. This year before I introduce you to the annual report I make the same plea, in order that we can collaboratively continue to learn from one another and address variation in service provision and patient outcomes.

Author and teacher Paul Solarz has inspired many others to achieve greater and more active student engagement for learning. He says ''Collaboration allows us to know more than we are capable of knowing ourselves''. This must underpin our approach to the data submitted to CRANE and inform how we use that data for the benefit of current and future individuals born with a cleft.

In this spirit of collaboration and learning I invite you to take the time to read this 2025 report and reflect on its findings. The report contains details of the audit in England, Wales, Northern Ireland, and Scotland for children born with a cleft between January 2022 and December 2024, and outcomes for 5-year-old children born in 2016-18. The registry now holds details of 25,862 children, amassed since CRANE began in 2000. Over the last 25 years CRANE has developed and continues to do so. You will find in this report details of the Organisational Audit completed by CRANE, with an impressive 100% response rate from Cleft Services. This represents a significant review of current services including workforce, access and timing of treatment. It highlights variation in service provision that has the potential to impact quality and safety of care. For example, 30% of services reported delays to optimum timing for treatment.

The report begins with a helpful key findings and recommendations section, which sets out the main registry and outcome findings and proposes actions for stakeholders. The recommendations are similar to last year and relate to the ongoing goal of improving data completeness and reducing variation in specialty specific outcomes. It is encouraging to see an increase in verified consent rates compared to last year, and a significant improvement in data completeness rate for speech outcomes of 70% compared to 54% in 2024. However, verified consent status ranged between 71% and 90% across Cleft Services (with a target of 100% of those registered). CRANE continues to support services to achieve high rates of consent, with database guides and regular learning and Q&A events.

In the audit outcomes chapter, you will find data relating to a range of specialty specific outcomes, reflecting the multifaceted nature of cleft, and the multidisciplinary approach to care. This year CRANE have been able to report risk adjusted data for dental (decayed, missing and filled teeth) and speech outcomes. This increases the level of confidence we can have when interpreting this data for improvement purposes. Once again, I am impressed with how Cleft Services have positively engaged with the outlier reporting process, piloted in 2020/21 and fully adopted from this 2025 cycle. This level of engagement and transparency is essential for a just culture in national audit, that balances accountability with fairness and learning.

Finally, I would like to thank CRANE for this report, and to echo the authors' acknowledgment of all the children, families and services who have contributed to it. I will be stepping down as chair soon, but I have no doubt that the Cleft Development Group will continue to encourage and support all services to engage with CRANE as part of a wider process of continuous improvement and the goal of reducing inequalities for children born with cleft.

Wishing you all a happy festive season and a bright 2026!

GMPhippen

Ginette Phippen
Chair of the Cleft Development Group

Executive summary

RCS

CRANE

Cleft Registry & Audit NEtwork

Annual Report 2025

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

Registry information

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

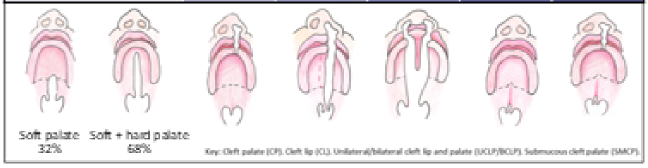
901 children were born with a cleft in 2024.

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

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

Distribution of cleft type

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



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

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

Audit outcomes at 5 years of age

Body mass index

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

Dental health

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

Facial growth

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

Speech

54% of children with a cleft palate (+/-cleft lip) had speech comparable to their peers.

74% achieved speech without evidence of structurally-related speech difficulties.

62% achieved speech without cleft-related speech characteristics that may require therapy or surgery.

Speech varies according to cleft type.

Psychology

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

Development work

Organisational Audit Report

100% of cleft services responded to the first comprehensive organisational audit (OA) of cleft care since the CSAG report in the late 1990s.

The OA findings highlight considerable variation in commissioned services, staffing levels, and access to diagnostic and operative facilities.

A well-resourced and consistent model of cleft care delivery is required in the UK.

Conference Presentations

CRANE was involved in **7** different presentations across both the 15th International Congress of Cleft Lip/ Palate and Related Craniofacial Anomalies (**CLEFT2025**) in Japan and the Craniofacial Conference (**CFSGBI 2025**) in Newcastle.

We value sharing our findings with health professionals and patient representatives.

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

Key findings and recommendations 2025

Source	Findings	Recommendations
Registry		
Patient characteristics: Cleft type, Robin Sequence and sex		
Chapter 3, Sections 3.1.1-3.1.4	• There were 2,673 CRANE-registered children born 2022-2024, equating to 891 per year. • 55% of registrations were boys and 45% were girls. • 43% had cleft palate (CP), 26% had cleft lip (CL), 20% had unilateral cleft lip and palate (UCLP), 9% had bilateral cleft lip and palate (BCLP), <2% had submucous cleft palate alone (SMCP) and <1% had SMCP with CL (SMCP+CL). • 23% of all children with CP were reported to have Robin Sequence. This rate increased to 40% for those with a complete cleft of both the soft and hard palate.	1. It is recommended that services ensure RS status is accurately reported for all children with a CP.
Gestational age and birthweight		
Chapter 3, Sections 3.1.5-3.1.6 **Indicators[2]: #1 & #2**	• 75% of CRANE-consented children had a recorded gestational age and birthweight. • The average gestational age of babies born with a cleft in 2022-24 was 38.4 weeks. • 13% of babies with a known gestational age were born prematurely (<37 weeks' gestation). This compares to 8% in the general population[3]. All cleft types had higher rates of preterm birth than the background rate. • The average birthweight was 3,141g. • Children with a BCLP, CP, SMCP, and SMCP+CL had significantly lower birthweights than those with CL. • 14% of babies with birthweight reported had a low birthweight (<2,500g). This compares to 7% in the general population[2]. The rate among babies born at term was 6%, while the corresponding rate in the general population is 3%.	2. Cleft Services should ensure that gestational age and birthweight are reported for all CRANE-consented cases, so that the data reported becomes more representative of children born with a cleft. 3. The research community should validate and further investigate the higher percentage of premature births and babies with low birthweight among children diagnosed with a cleft compared to rates in the general population. The increased prevalence of low birthweight among babies born at term from ethnic minority groups also requires further investigation. 4. CRANE will engage with the Royal College of Midwives (RCM) and Royal College of Obstetricians and Gynaecologists (RCOG) to communicate our findings.
Timing of diagnosis		
Chapter 3, Section 3.2 **Indicator: #3 & #4**	• 98% of CRANE-registered children had diagnosis time reported. • 78% of children with a cleft involving the lip were diagnosed antenatally, while 74% of children with CP were diagnosed before or within 24hrs of birth. Timely detection of CP increased to 84% when including diagnoses within 72 hours of birth. These rates remain unchanged from the previous reporting period (2021-2023 births).	5. CRANE will seek to collaborate further with the clinical workforce to identify barriers to recording timing of diagnosis for all registrations in CRANE. 6. CRANE will continue to monitor rates of antenatal and timely diagnoses to ensure issues are highlighted, as well as opportunities for learning and areas for improvement identified.

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[2] CRANE core indicators are detailed in **the supplementary tables**.

[3] Birth characteristics in England and Wales

	• Timely diagnosis varies according to extent of cleft involvement. Only 28% of children with SMCP were diagnosed before or within 24hrs of birth. • Despite improvement in the timely detection of CP over the last decade, 1 in 4 children still have a diagnosis beyond 24 hours from birth.	7. Cleft Services with lower levels of timely diagnoses should liaise with referring maternity services to notify them that they may be missing opportunities to detect clefts of the lip and palate in a timely manner. 8. Cleft Services should extract data from CRANE to identify late diagnoses and the Clinical Nurse Specialist or Clinical Lead should feed this information back to the relevant maternity services, ensuring open communication with Maternity Leads, NIPE leads and Neonatal Clinical Leads.
Referral to and contact with Cleft Services		
Chapter 3, Section 3.3 **Indicators: #5 to #8**	• 85% of CRANE-registered children had a recorded postnatal referral time. Of these, 82% were referred to a Cleft Service within 24 hours of birth. This rate varied significantly according to Cleft Service and cleft type, but it has not changed since the previous reporting period (2021-2023 births). • 97% of registered children had a recorded contact time. 88% of families were contacted by the Clinical Nurse Specialist (CNS) within 24 hours of antenatal referral, 95% were contacted by their Cleft Service within 24 hours of postnatal referral, and 86% were visited by a CNS within 24 hours of referral. These rates varied significantly according to Cleft Service.	9. Cleft Services should record the contact and referral time of all registrations by working with referring obstetric, midwifery and neonatal units to improve the capture of this information. 10. Regional variation in the percentage of children referred, contacted and visited within 24 hours demonstrates that some Cleft Services have high levels of referrals and contacts within 24 hours. They should share their best practice recommendations with Cleft Services with lower rates.
CRANE consent		
Chapter 4 **Indicator: #9**	• Consent status was verified for 90% of children born 2022-24 and 92% of those born 2016-18. This meant they had given informed consent or declined consent for CRANE to collect outcome data. Of those with verified consent, 97% gave consent. • Consent verification rates varied significantly according to Cleft Service, ranging from 71% to 100%.	11. Cleft Services with high consent rates should share their best practice recommendations. 12. Cleft Services with below average consent rates should review their procedures to identify opportunities to make improvements.
Outcomes at 5 years		
Child growth		
Chapter 5, Section 5.1 **Indicator: #10 & #11**	• 51% of CRANE-consented children born 2016-2018 had a recorded height and weight. • 83% of children with growth data had a healthy body mass index (BMI). This compares to 77% in the general population of 5-year-olds[4]. • According to BMI categorisation, 4%[5] were underweight, 8% overweight and 5% obese. Corresponding rates in the general population are 1%, 12% and 10%, respectively.	13. Cleft Services should aim to assess children's weight and height at age 5 and improve the reporting of these measures in the CRANE Database. This will facilitate more meaningful comparisons between subgroups in the future. 14. CRANE will continue to liaise with CDG members and the nursing CEN to encourage all services to collect this data. 15. Research should explore reasons why the BMI distribution differs between the cleft and general population of 5-year-olds.

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[4] National Child Measurement Programme Tables, England 2021/22 and 2022/23 School Years [Last accessed: 12/07/2024]

[5] This may be overestimated due to data errors in heights submitted by South Wales (see Outlier Response).

Dental health		
Chapter 5, Section 5.2 **Indicators: #12 to #16**	• 56% of CRANE-consented children had recorded dmft scores, with rates improving over the three birth years. • Dental decay was experienced by 39% of children (having at least one decayed, missing or filled tooth (dmft >0)) and 16% of children were classified as having extensive caries (dmft >5). Rates were highest among children with BCLP and lowest among those with CL. • The proportion of children experiencing dental decay varied significantly across Cleft Services, even after adjusting for deprivation, country, Robin Sequence, birth year, cleft type, extent of hard palate involvement and sex. • The average Treatment Index (rate of treated disease) was 75%, and the average Care Index (having received the appropriate care at the earliest possible stage) was 67%. Both indexes varied across Cleft Services.	16. Cleft Services should have at least 80% of all children with a cleft assessed at the age of 5 years by a calibrated specialist in paediatric dentistry, in line with paediatric dentistry CEN standards, and the dmft and dental anomalies information should be recorded in the CRANE Database. 17. All children with a cleft should have a recommended care plan established by collaborative work between the family's local dental care provider and the specialist paediatric dentist in the Cleft Service. This should (a) treat the child as per the high-risk category of the dental health toolkit (Delivering Better Oral Health), (b) provide routine dental care within the general dental service, and (c) provide specialist level care including age-specific dental development assessment and treatment under inhalation sedation and general anaesthesia within the Cleft Service. 18. The COVID-19 pandemic had a significant impact on access to dental care in the early years for this population of patients, particularly those from more deprived areas. Anecdotal and local evidence suggests that access to NHS dental care has still not recovered to pre-pandemic levels particularly in some regions of the country. All children with a cleft should have access to a local NHS dental provider by their 1st birthday to instigate early preventive advice and build a positive dental relationship.
Facial growth (for children with complete UCLP)		
Chapter 5, Section 5.3 **Indicator: #17 & #18**	• 56% of CRANE-children with a complete UCLP had 5-year-old Index scores reported. • 54% had scores reflecting 'good' dental arch relationships, 31% 'fair' and 16% 'poor'.	19. Cleft Services should aim to take records of all children born with a complete UCLP before they turn 6 years of age to support an external facial growth assessment using the 5-year-old index. These records may take the form of study models or clinical photographs with a recording of the overjet *(the horizontal gap between the front teeth)*. Study models can be made from dental impressions with a bite record or digital scans of the teeth and bite. Photography guidance should be sought from the IMI Guide to Good Practice for Cleft Lip and Palate (template 2a) 20. 100% of available records should be submitted for external scoring and validation to support benchmarking. 21. The research community should undertake to compare UK facial growth outcomes with those in other countries and evaluate the predictive value of the 5-year-old Index in the UK.

Speech (for children with CP, UCLP and BCLP)		
Chapter 5, Section 5.4 **Indicators: #19 to #22**	• 70% of CRANE-consented children with a cleft affecting the palate had all 16 CAPS-A speech parameters reported, representing a substantial improvement compared to 54% reported last year (2024 CRANE report). CAPS-A scores are used to report on the national speech outcome standards. This represents a positive aspect of Post COVID recovery in cleft SLT services. • 54% met speech outcome standard 1: The achievement of speech with no evidence of a structurally related problem and no cleft speech characteristics requiring intervention. • 74% met speech outcome standard 2a: The achievement of speech without evidence of a structurally related speech difficulty. • 62% met speech outcome standard 3: The achievement of speech without evidence of significant cleft-related speech characteristics, which may require therapy or surgery. • 15% of children had secondary surgery for speech purposes before the age of 5 years. • The proportion of children meeting each standard varied significantly across Cleft Services, even after adjusting for cleft type, extent of hard palate involvement, Robin Sequence status and sex.	22. Cleft Services should ensure that all children with a cleft affecting the palate have their speech at 5 years assessed and reported to CRANE. 23. Cleft Services should work together to explore reasons for variation in speech outcomes and learn from best practice in the UK.
Psychology screening		
Chapter 5, Section 5.5 **Indicators: #23 to #26**	• 72% of CRANE-consented children had recorded TIM scores, representing a substantial improvement compared to 57% reported last year (2024 CRANE report). • 92% were seen by a psychologist before the age of 6 years and a psychosocial screen was completed or psychological input arranged (Tiers of Involvement Measure 1 to 6 referred to as 1+). • The proportion seen by a psychologist varied significantly according to Cleft Service, but not according to cleft or patient characteristics.	24. TIM scores should be recorded for all CRANE-consented children. 25. Cleft Clinical Psychology teams should aim to see all children and families before the age of 6 years and ensure that psychological support is provided if appropriate. 26. Cleft Services should continue to collect Cleft Q data for children who are 10 years of age, born from 2015 onwards, and record this in CRANE once available on the Database.
All outcomes at 5 years		
Chapter 5	• An outlier process was applied to children's outcomes at 5 years of age. Cleft Services were permitted to provide a response to being identified as a positive or negative outlier.	27. All Cleft Services should work together to explore reasons for variations in data completeness and outcomes at 5 years of age.
Data quality – throughout report		
Chapters 3 to 5	• There was significant variation in data completeness for registrations and for specialty-specific outcomes across Cleft Services. • Overall, there was minimal change in data completeness of registry data items compared to rates reported last year (2024 CRANE report). However, these indicators are generally well-reported (75%-99% data completeness). • For all 5-year-old outcome measures, data completeness improved substantially (by 11-16%) compared to the rates reported last year (2024 CRANE report). • Recovery from the COVID-19 pandemic has significantly affected some specialties' ability to submit 5-year-old outcome data.	28. Cleft Services identified as negative outliers for data completeness are encouraged to consider methods for improving the capture and reporting of data. CRANE will facilitate this with its annual 'Making it Better' webinar that highlights areas of best practice for learning purposes. 29. Cleft Services, Clinical Excellence Networks (CENs) and CRANE should work together to identify and overcome barriers to collecting and submitting data.

Database development work		
Organisational Audit		
Chapter 6, Section 6.1	• CRANE conducted an Organisational Audit of Cleft Services at the request of NHS England Specialist Commissioning. • 100% of Cleft Services responded. • There was considerable variation in commissioned services, staffing levels, and access to diagnostic and operative facilities. • Workforce shortages and recruitment challenges are widespread, especially in psychology, orthodontics and paediatric dentistry. • Equitability of access remains a challenge across geography and specialties, especially for paediatric dentistry and speech and language therapy. • 80% of services reported having concerns about delayed detection or delayed referral of clefts, but only 40% said they were adequately funded to engage in training professionals outside of their service. • Most services aimed to repair the lip by 3 or 4 months and the palate by 9 months; however, 33% reported delays to these timings during 2024. • Services are highly engaged with the CRANE Database and value its role in benchmarking and quality improvement.	30. Investment should be made to expand and retain specialties impacted by workforce shortages, including psychology, orthodontics and paediatric dentistry. 31. Commissioners and providers should work together to improve equitable access to cleft-related specialties across each region, prioritising paediatric dentistry and speech and language therapy where gaps exist. 32. Early detection of clefts should be facilitated through funded training and partnerships. Education and training should be provided for midwives, neonatal teams, health visitors, tongue tie specialists and GPs. 33. Every Cleft Service should have a funded data co-ordinator role, who supports national clinical audit.
Peer-reviewed publications and presentations		
Chapter 6	• CRANE was involved in three oral presentations at the Craniofacial Society of Great Britain and Ireland Annual Conference in April 2025 and six oral presentations at the 15th International Congress on Cleft Lip/Palate and Related Craniofacial Anomalies (CLEFT2025).	34. Collaboration is key to sharing CRANE data and facilitating research that informs clinicians, families and policy makers. CRANE should be adequately resourced to undertake continual development work and share information with key stakeholders at national and international meetings to ensure work has greatest impact for those born with a cleft in the UK and beyond.

1. Introduction

The Cleft Registry & Audit NEtwork (CRANE) Database is a national register that was established in 2000 to collect information on children born alive with a cleft lip and/or palate in England and Wales[6]. Northern Ireland officially joined in 2015, and in January 2023 we welcomed Scotland. This means that CRANE is now a UK-wide cleft registry and audit. The geographical representation of the Cleft Services is detailed in **the supplementary tables**. The Database collects birth, demographic and cleft diagnosis information. It also collects information about cleft-related treatment and outcomes.

This Annual Report presents findings from data submitted to the CRANE Database[7] and has four main sections:

- **Registry Information:** Patient characteristics, diagnosis times, and early contact care information, including timing of referral to and contact by Cleft Services for children born 2022-2024.
- **Consent:** Consent levels for those born 2022-2024, reflecting recent registrations, and those born in 2016-2018, reflecting those eligible for 5-year outcome reporting.
- **Audit Outcomes at 5 years of age:** Cleft-related outcomes for CRANE-consented children at 5 years of age who were born 2016-2018.
- **Database development work:** Development activity undertaken by the CRANE team over the last 12 months. This year we present a summary of the Organisational Audit of Cleft Services across the UK, carried out by CRANE in 2025 at the request of NHS England.

This Annual Report aims to provide feedback to all stakeholders involved in cleft care, highlighting areas of success and areas requiring improvement. It does so by reporting against process and outcome indicators, agreed by the UK NHS Cleft Development Group (CDG) and Clinical Excellence Networks (CENs), as detailed in **the supplementary tables**.

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[6] For further information on the background to the CRANE Database please visit https://www.crane-database.org.uk/

[7] Registered in the CRANE Database by 30 June 2025.

2. Methods

2.1. Datasets

2.1.1. CRANE

CRANE is an online custom-built secure database that holds registry and audit information on children born with a cleft lip and/or palate in the UK. The CRANE Database collects data pertaining to a child's birth, demographics, type of cleft, time of diagnosis, time of referral to a Cleft Service, and time of first contact between the family and a Cleft Service. The CRANE Database also collects information about cleft-related treatment and outcomes for those with consent. Each child born with a cleft in the UK should be referred to one of 14 Cleft Services (as listed in **the supplementary tables**), who are responsible for registering children on the CRANE Database.

Since 2000, the CRANE Database has been able to act as a national register of cleft-affected births by collecting some basic information on all children born with a cleft being treated by the specialist Cleft Services. In England and Wales, this information is collected without consent, under a legal provision called Section 251, granted by the Secretary of State for Health and Social Care, following advice from the Confidential Advisory Group (CAG). Additional information on cleft-related treatment and outcomes is collected for children whose parents have consented to their child's data being submitted to the national database. Parental consent is usually obtained by Cleft Services at some point between referral and the first primary repair. A coordinator within each Cleft Service submits data to the CRANE Database on the children referred to them. Once a record has been created on the CRANE Database for a particular child, it can later be updated with further information.

CRANE cohort

The children and timeframes covered in each section and sub-section are indicated in the cohort summaries at the beginning of each chapter. Broadly, timeframes are the most recent years of available data: 2022-2024 births for registry information and 2016-2018 births for 5-year outcomes.

Children whose parents have not consented to their data being used by CRANE have been excluded from the sections and tables on: (1) gestation and birthweight, and (2) 5-year outcomes, as the data presented in these sections and tables are not collected for non-consenting cases.

For 5-year-old cleft-related outcomes, children with a submucous cleft palate alone are excluded from analyses due to the variation in their diagnosis/presentation age. This year, we have also excluded children whose cleft care was transferred to another service between treatment and outcome assessment (2 months to 5 years) from service-level reporting, as children who transfer between services may have different outcomes to those receiving all of their cleft care from one team.

Cleft type

Cleft type is defined according to reported LAHSAL codes. The LAHSAL code is used to classify clefts, with each letter relating to one of the six parts of the mouth that can be affected by a cleft:

L	**A**	**H**	**S**	**A**	**L**
Right Lip	Right Alveolus	Hard palate	Soft palate	Left Alveolus	Left Lip

The code also indicates whether there is a complete cleft (upper case letter, e.g. L, A, H and/or S), an incomplete cleft (lower case letter, e.g. l, a, h and/or s), or no cleft (left blank). Where LAHSAL has not been reported (in 3% of all registered cases), cleft type is either based on the type reported by the region/ unit registering the child or left as 'unspecified'. The four main cleft types include cleft lip (CL), cleft palate (CP), unilateral cleft lip and palate (UCLP) and bilateral cleft lip and palate (BCLP). The submucous tick box on the database is used to further classify clefts as submucous cleft palate (SMCP) alone or SMCP with cleft lip.

Missing data

Missing data have been excluded from the denominators presented in all tables, figures and supplementary tables of this report, except for tables and figures relating to data completeness (see **the supplementary tables** for a breakdown of those reported for each outcome). When outcomes are not available, Cleft Services are requested to report a reason for this from a drop down: Patient deceased or emigrated; patient transferred in/out of area; clinically contraindicated; lack of staff/facilities/equipment; patient did not attend/cancelled/did not consent or cooperate; other reason. Data completeness is described for each indicator presented throughout this report. For risk-adjusted outcomes, multiple imputation was used to predict missing covariates used within the risk-adjustment models for dental and speech outcomes.

2.2. Statistical analyses

Statistical analyses were tailored to the different types of outcome data. Proportions describing categorical outcomes (e.g. achieving or not achieving cleft speech standard 1) were compared across different exposure categories, such as year of birth and cleft type, using Chi-Square Tests. For normally distributed continuous outcome data (e.g. birthweight), linear regression was used to compare differences between exposure categories. For non-parametric continuous outcome data (e.g. Treatment Index and Care Index), a Kruskall-Wallis test was used to compare differences between exposure categories. Logistic regression was used to risk-adjust dental and speech outcomes. For dental dmft funnel plots, service-level rates were adjusted for Index of Multiple Deprivation, country (due to country-specific indices of deprivation), Robin Sequence status and birth year. For speech outcome funnel plots, service-level rates were adjusted for cleft type, extent of hard palate involvement, Robin Sequence status and sex.

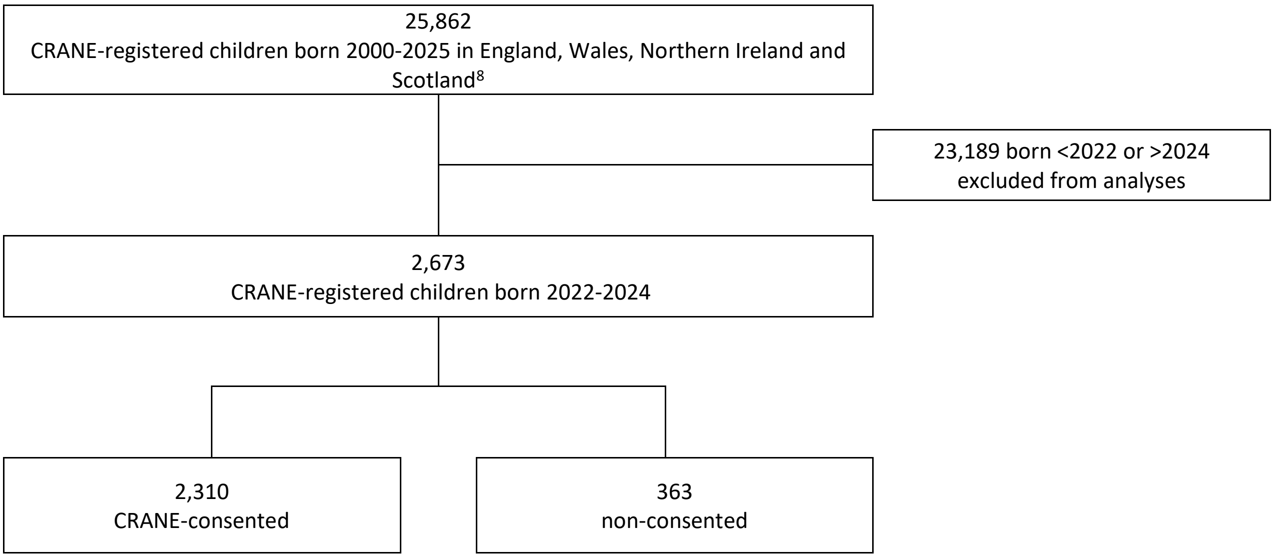
2.3. Supplementary tables

Supplementary tables published alongside the report provide service-level information on data completeness and outcomes. This information is used to produce the funnel plots included in this report. Data completeness and outcomes are also summarised by patient characteristics (year of birth, cleft type, sex and ethnicity), with p values reflecting statistical significance based on Chi Square tests. Information on age of assessment and reasons for not collecting the outcome are also summarised.

3. Registry information

Cleft Services should register all children born alive with a cleft in the UK. This chapter details the characteristics of CRANE-registered children born with a cleft lip and/or palate in 2022-2024. The timing of diagnosis, referral to Cleft Services and contact with families is also provided. This is key information for cleft care planning. Figure 3.1 shows the children eligible for reporting.

Figure 3.1. CRANE cohort eligible for inclusion in this chapter.



Cohort summary	
Data source	The CRANE Database. Extract taken: 30 June 2025
Birth years	Three years: 2022 to 2024
Countries	England, Wales, Northern Ireland and Scotland
Inclusions	CRANE-registered children[9], including those without a specified cleft type and those with a submucous cleft palate, unless stated otherwise.
Exclusions	None, unless stated otherwise.
Notes	• Not subject to outlier policy but funnel plots provided to demonstrate variation in rates across services. • Data are not risk adjusted.
Legal basis for data collection	The data used for this section are collected for all registered cases under a 'Section 251' exemption (of the NHS Act 2006 and its current regulations, the Health Service (Control of Patient Information (CPI)) Regulations 2002), with approval from the Confidentiality Advisory Group (CAG) for the disclosure of CPI held by the CRANE Database. Gestation and birthweight are exceptions to the Section 251 exemption and are collected only for children whose families have given informed consent to outcomes data collection by the CRANE Database.

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[8] Scotland joined in January 2023 and have two years (births in 2022 and 2023) of registrations only.

[9] 11 children who died before reaching two years of age are included in this registration chapter.

3.1. Patient and birth characteristics

For the most recent three-year reporting period (2022-2024 births), total number of registrations ranged from 94 to 334 between Cleft Services (see ‘Registrations 2022-24’ in Supplementary tables). This section describes the patient characteristics of these registrations.

Recommendations: Patient and birth characteristics
• The wide range in reported rates of RS between Cleft Services suggests that there is potential under- and over-reporting of this condition. It is recommended that services work to agree consensus on clinical thresholds for classifying RS. RS is a known determinant of outcome for speech and it is important that accurate RS status is recorded to allow appropriate risk-adjustment of future speech results for each service. • Cleft Services identified as negative outliers for data completeness are encouraged to consider methods for improving the capture and reporting of these data items to CRANE. • The research community should validate and further investigate the higher percentage of premature births and babies with low birthweight among children diagnosed with a cleft compared to rates in the general population. The increased prevalence of low birthweight among babies born at term from ethnic minority groups also requires further investigation. • Maternity services should be made aware that an antenatal cleft diagnosis is a risk factor for premature birth and low birthweight. • CRANE will engage with the Royal College of Midwives (RCM) and Royal College of Obstetricians and Gynaecologists (RCOG) to communicate findings.

3.1.1 Sex

Data completeness: Sex	
Raw data	‘Patient characteristics 2022-24’ in **the supplementary tables**
Denominator	2,673 CRANE-registered children
What did we find? 	99.8% of CRANE-registered children had their sex specified (Cleft Service range: 98%-100%, p<0.001). This has not changed compared to the previous reporting period (births 2021-2023).

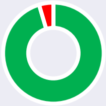
Outcome: Sex ratio	
Denominator	2,666 children with sex reported
What did we find? 	• There were more boys (55%) than girls (45%) (Cleft Service range for boys: 44%-61%, p=0.073). • The sex ratio varied significantly according to cleft type (p<0.001). There were more boys than girls with clefts involving the lip (range: 59% in CL - 69% in BCLP) and more girls (57%) than boys with clefts affecting only the palate.

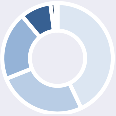
3.1.2 Ethnicity

Data completeness: Ethnicity	
Raw data	‘Patient characteristics 2022-24’ in **the supplementary tables**
Denominator	2,673 CRANE-registered children
What did we find? 	70% of CRANE-registered children had their ethnicity specified (Cleft Service range: 24%-100%, p<0.001). Ethnicity has only been collected since April 2021 and this is the first time it has been reported by CRANE.

Outcome: Ethnic group	
Denominator	1,865 children with ethnicity reported
What did we find? 	• 80% of children with ethnicity reported were classed as White, while 20% were from ethnic minority groups (Cleft Service range: 6%-30%, p<0.001). • Ethnic minority group representation was higher in females (23%) then males (18%) (p=0.017), but did not vary statistically according to cleft type (p=0.330).

3.1.3 Cleft characteristics

Data completeness: Cleft type specification	
Raw data	‘Patient characteristics 2022-24’ in **the supplementary tables**
Notes	LAHSAL code is used to categorise cleft type and determine the laterality of the cleft lip and the completeness of the cleft.
Denominator	2,673 CRANE-registered children
What did we find? 	• 95% of CRANE-registered children had their cleft type specified (Cleft Service range: 71%-100%, p<0.001). This compares to 96% of those born 2021-2023 (CRANE, 2024). • Reporting varied slightly according to birth year (2022: 97%, 2023: 95%, 2024: 94%, p=0.041).

Outcome: Cleft type distribution and cleft characteristics	
Denominator	2,550 children with cleft type reported
What did we find? 	• 43% of children had a cleft palate alone (CP). Of these, 32% had a cleft affecting only the soft palate, 38% had a complete cleft of soft palate and incomplete cleft of hard palate, while 29% had complete involvement of both the soft and hard palate. • 26% of children had a cleft lip alone (CL). Of these, 56% were left-sided, 34% were right-sided and 10% were bilateral. Among those with a unilateral CL, the left:right ratio was 62%:38%. 12% of CL cases were reported to have a microform cleft lip. • 20% of children had a unilateral cleft lip and palate (UCLP). The left:right ratio was 59%:41%. Overall, 70% had a complete UCLP, defined as LAHS or HSAL LAHSAL codes. • 9% of children had a bilateral cleft lip and palate (BCLP). 55% had a complete BCLP. • <2% of children had submucous cleft palate (SMCP) alone. • <1% of children had submucous cleft palate with cleft lip (SMCP+CL). • 4% of children were reported to have a syndrome. This rate ranged from 0% among those with SMCP+CL to 7% among those with CP. • There were no significant differences in the distribution of the four main cleft types (CL, CP, UCLP & BCLP) across Cleft Services (p=0.061); however, Northern Ireland registered a much higher proportion of children with SMCP (15% of their registrations) than the overall average (2% of registrations).

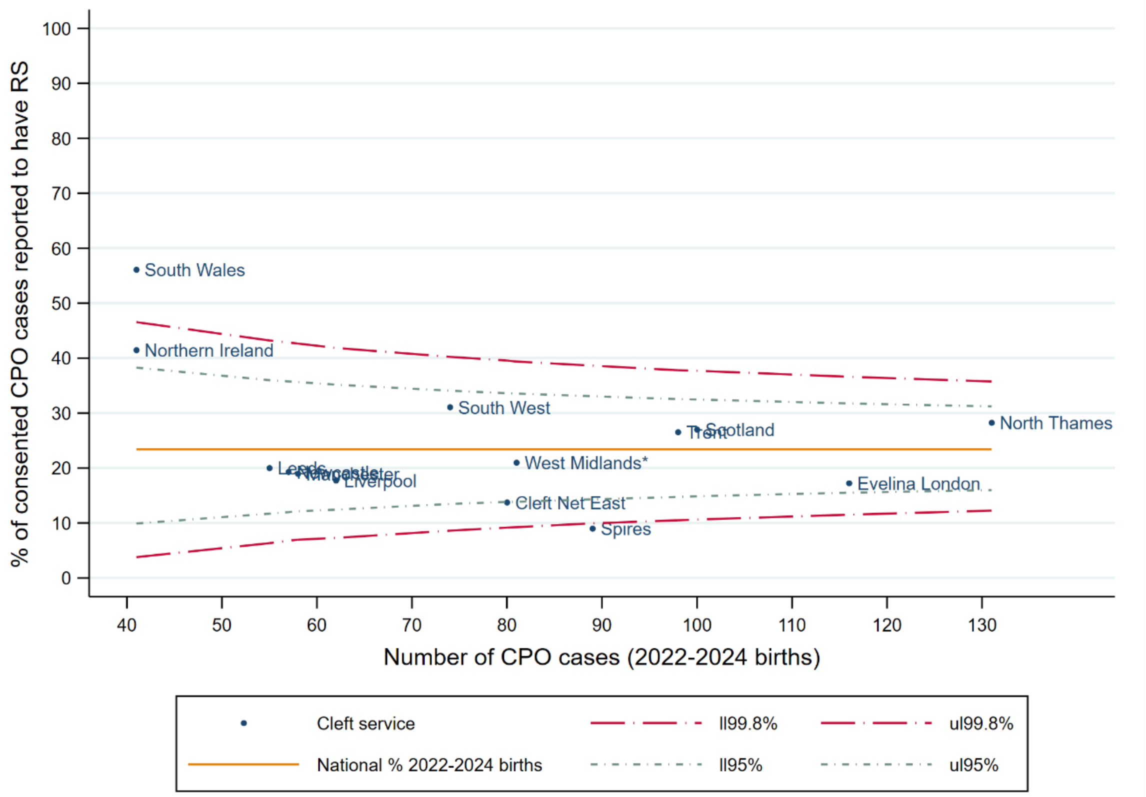
3.1.4 Robin Sequence

Data completeness: Robin Sequence status	
Raw data	‘Patient characteristics 2022-24’ in **the supplementary tables**
Definition	Robin Sequence (RS) is a congenital birth condition characterised by micrognathia, glossoptosis, airway obstruction and failure to thrive, with or without a cleft affecting the palate. The classification of a child with RS varies between Cleft Services due to ongoing debate around diagnosis thresholds. Internationally there is an ongoing series of consensus meetings relating specifically to RS.
Notes	For children with a cleft palate alone, services report RS status (present or absent).

Denominator	1,084 CRANE-registered children with cleft palate alone (CP) (excludes those with SMCP)
What did we find? 	- 94% of CRANE-registered children with cleft palate alone had their RS status (present or absent) specified (Cleft Service range: 44%-100%, p<0.001). This compares to 91% for the previous reporting period (births 2021-2023). - Reporting varied by ethnicity (White: 98%, ethnic minority groups: 94%, p=0.02), but not by birth year (p=0.586).

Outcome: Prevalence of Robin Sequence among children with a cleft palate alone	
Notes	Not subject to outlier policy but funnel plot provided to demonstrate variation in rates across services.
Denominator	1,084 children with cleft palate alone (CP) (excludes those with SMCP)
What did we find? 	- 23% of children with cleft palate alone were reported to have RS (Cleft Service range: 9%-56%, p<0.001). This rate equates to an annual average of 84 children born with RS between 2022-2024. - 71% of children with CP were confirmed as not having RS (Cleft Service range: 30%-89%). A further 6% did not have their status confirmed and are therefore assumed not to have it. - Prevalence of RS varied significantly according to extent of cleft involvement (LAHSAL code 's': 5%. 'S': 9%, 'Sh': 24%, 'SH': 40%, p<0.001), but not according to birth year (p=0.504) or sex (p=0.545).
Outliers	High: 1. South Wales (56%) Low: 1. Spires (9%), 2. Cleft Net East* (14%) * Low alert status for two consecutive reporting periods and therefore classed as outlier.

Figure 3.2. Funnel plot showing the percentage of CRANE-registered children with cleft palate alone, born 2022 to 2024, with RS, according to Cleft Service.

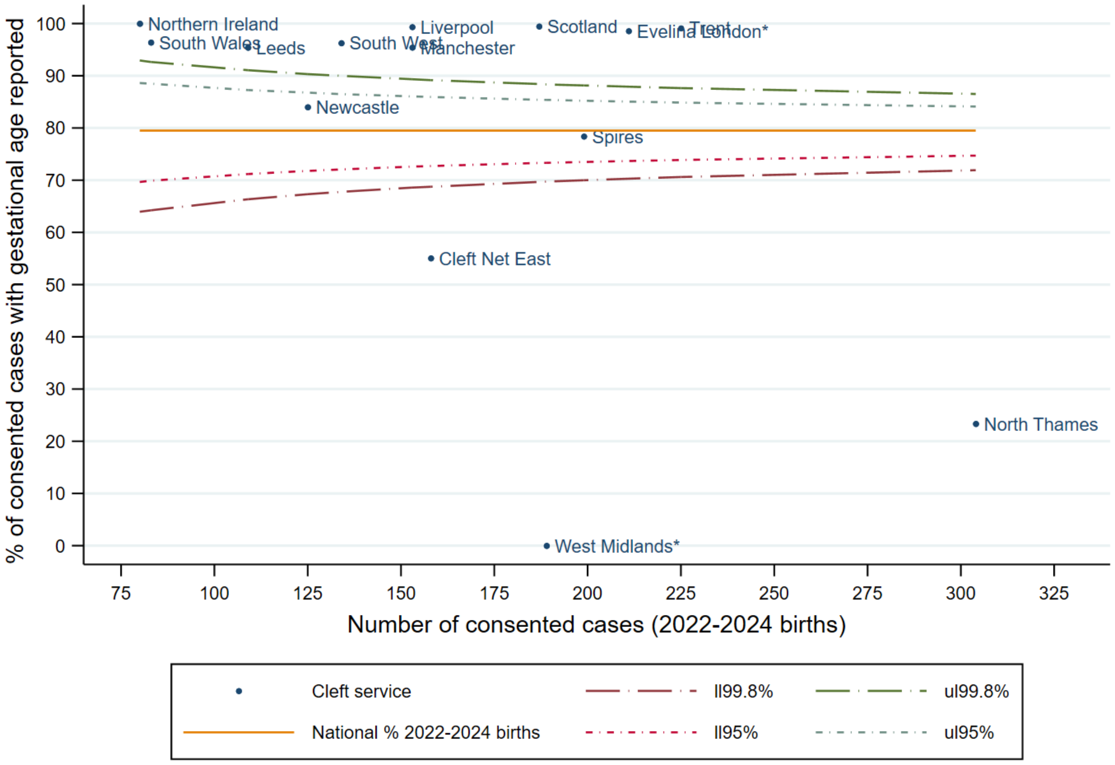


Note: Funnel plot centred on the national percentage (23.3%) of children (born 2022-2024) reported to have RS.

3.1.5 Gestation

Data completeness: Gestational age	
Raw data	'Gestation 2022-24' in **the supplementary tables**
Indicator	#1 - Gestational age recorded for all eligible children with consent
Notes	Funnel plot is centred on the revised national rate after excluding data from services identified as negative outliers for consent verification (West Midlands and Evelina London).
Denominator	2,310 CRANE-consented children
What did we find? 	• 75% of CRANE-consented children had a recorded gestational age (Cleft Service range: 0%-100%, $p<0.001$). This has not changed compared to the previous reporting period (births 2021-2023). • Reporting varied significantly according to birth year (2022: 73%, 2023: 78%, 2024: 73%, $p=0.042$), but not by known cleft type ($p=0.688$), sex ($p=0.433$) or ethnicity ($p=0.15$). • <1% had a reason why gestational age data were not collected. • 25% were missing data and a reason for not collecting data.
Outliers	Positive: 1. Northern Ireland (100%), 2. Scotland (99%), 3. Liverpool (99%), 4. Trent (99%), 5. Evelina London (99%), 6. South Wales (96%), 7. South West (96%), 8. Manchester (95%) 9. Leeds (95%), Negative: 1. West Midlands (<1%), 2. North Thames (23%), 3. Cleft Net East (55%)

Figure 3.3. Funnel plot showing the percentage of CRANE-consented children, born 2022 to 2024, with gestational age reported, according to Cleft Service.



Note: Funnel plot centred on the revised national percentage (79.5%) of children (born 2022-2024) with gestational age data reported.

Outcome: Gestational age	
Benchmarks	Among babies born 2022-2024 in the general population of England & Wales, 8% had premature births (<37 weeks' gestation)[10].
Denominator	1,727 CRANE-consented children with gestational age reported

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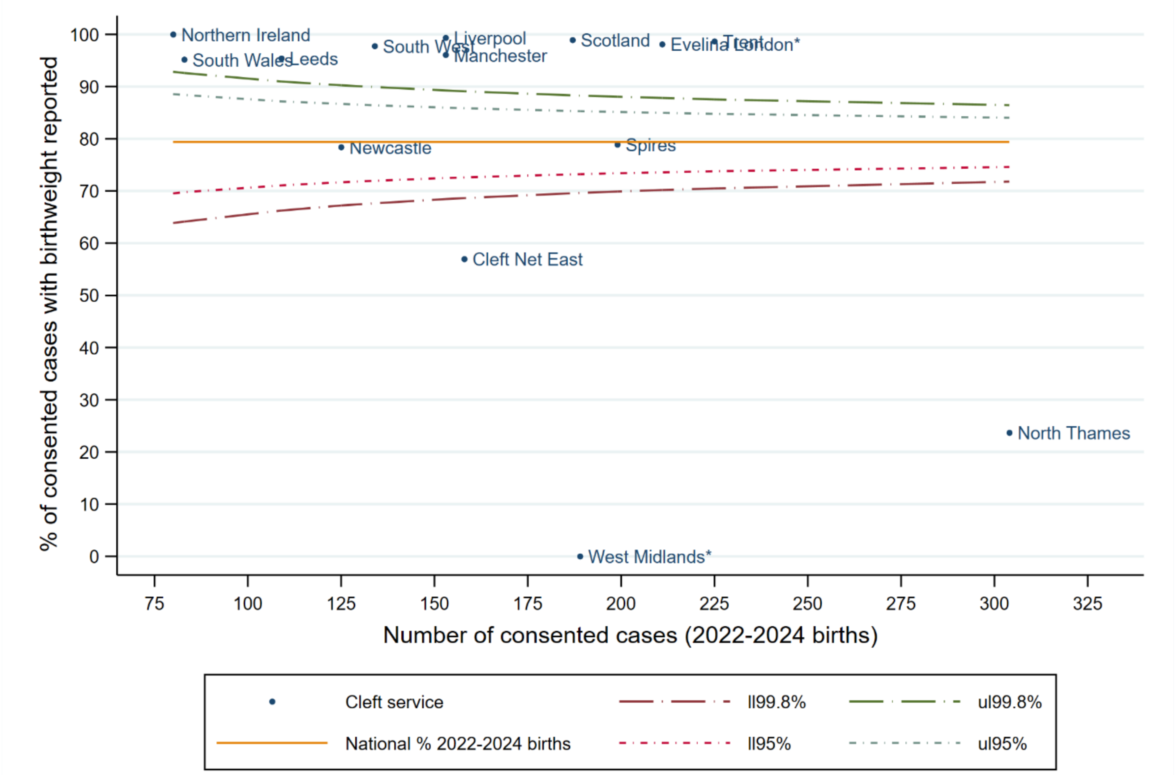
[10] Birth characteristics in England and Wales. Available at: Live births - Office for National Statistics (ons.gov.uk) [Last accessed: 13/10/2025]

What did we find?	• The mean gestational age was 38.4 weeks (95% CI 38.3-38.5 weeks). • The percentage of premature births among children with gestational age reported was 13% (Cleft Service range 8%-17%, p=0.580) and is higher than in the general population (8%). • The percentage of premature births did not vary significantly according to known patient characteristics (cleft type, p=0.080; sex, p=0. 707; ethnicity, p=0.334; birth year, p=0.907).

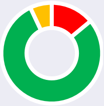
3.1.6 Birthweight

Data completeness: Birthweight	
Raw data	'Birthweight 2022-24' in **the supplementary tables**
Indicator	#2 - Birthweight recorded for all eligible children with consent
Notes	Funnel plot is centred on the revised national rate after excluding data from services identified as negative outliers for consent verification (West Midlands and Evelina London).
Denominator	2,310 CRANE-consented children
What did we find?	• 75% of CRANE-consented children had a recorded birthweight (Cleft Service range: <0%-100%, p<0.001). This is similar to the previous reporting period (births 2021-2023). • Reporting did not vary significantly according to birth year (p=0.131), known cleft type (p=0.463), sex (p=0.464) or ethnicity (p=0.28). • <1% had a reason why birthweight data were not collected. • 25% were missing data and a reason for not collecting data.
Outliers	Positive: 1. Northern Ireland (100%), 2. Liverpool (99%), 3. Scotland (99%), 4. Trent (99%), 5. Evelina London (98%), 6. South West (98%), 7. Manchester (96%), 8. Leeds (95%), 9. South Wales (95%) Negative: 1. West Midlands (0%), 2. North Thames (24%), 3. Cleft Net East (57%)

Figure 3.4. Funnel plot showing the percentage of CRANE-consented children, born 2022 to 2024, with birthweight reported, according to Cleft Service.



Note: Funnel plot centred on the revised national percentage (79.4%) of children (born 2022-2024) with birthweight data reported.

Outcome: Birthweight	
Definitions	• Low birthweight (LBW) is defined as <2,500g • Healthy birthweight is defined as 2,500g-3,999g • High birthweight (HBW) is defined as ≥4,000g
Benchmarks	Among babies born 2022-2024 in the general population of England & Wales, 7% had a low birthweight (LBW). Among those born at term, the rate was 3%[11].
Denominator	1,724 CRANE-consented children with birthweight reported. Of these, 1,493 were known to be born at term (≥37 weeks).
What did we find? 	• The mean birthweight was 3,141g (95% CI 3,110-3,171) among all children with birthweight reported, and was 3,289g (95% CI 3,263-3,314) among those born at term. • Mean birthweight varied according to cleft type. Compared to children with CL (birthweight 3,222g), children with CP (3,108g, p=0.003) and BCLP (3,102g, p=0.047), SMCP+CL (2,782g, p=0.016) and SMCP alone (2,869g, p=0.014) had significantly lower birthweights, while those with UCLP (3,161g, p=0.190), were not significantly different. • 14% of all children with birthweight reported had LBW (Cleft Service range: 9%-21%, p=0.525). The rate was 6% among those born at term (Cleft Service range: 4%-10%, p=0.787). These rates are twice as high as those reported for live births 2022-2024 in the general population (7% and 3%, respectively). • The percentage of children born at term with LBW varied according to sex (female: 7%, male: 4%, p=0.009) and ethnicity (white: 5%, ethnic minority group: 11%, p<0.001).

3.2 Timing of diagnosis

A cleft involving the lip is ideally identified during a routine ultrasound scan at around 20 weeks' gestation. Clefts affecting only the palate can be difficult to detect by ultrasound and are usually diagnosed immediately after birth or during the newborn physical examination (NIPE), performed within 72 hours of birth. Once a diagnosis takes place, the local Cleft Service should be notified.

Recommendations: Timing of diagnosis
• CRANE will seek to collaborate further with the clinical workforce to identify barriers to recording timing of diagnosis for all registrations in CRANE. • CRANE will continue to monitor rates of antenatal and timely diagnoses to ensure issues are highlighted, as well as opportunities for learning and areas for improvement identified. • Cleft Services with lower levels of timely diagnoses should notify referring maternity services that they may be missing opportunities to detect clefts of the lip and palate in a timely manner. • Cleft Services should extract data from CRANE to identify late diagnoses and the Clinical Nurse Specialist or Clinical Lead should feed this information back to the relevant maternity services, ensuring open communication with Maternity Leads, NIPE leads and Neonatal Clinical Leads.

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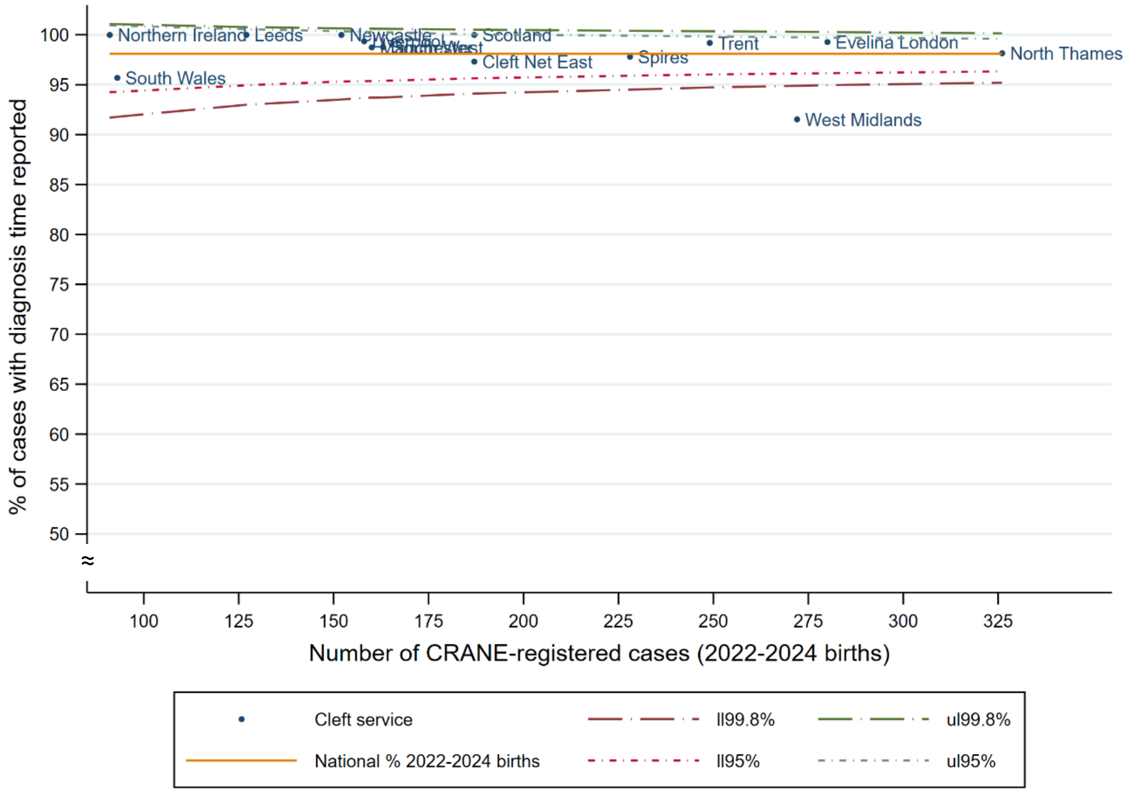
[11] Birth characteristics in England and Wales. Available at: Live births - Office for National Statistics (ons.gov.uk) [Last accessed: 13/10/2025]

Data completeness: Diagnosis time	
Raw data	'Diagnosis times 2022-24' in **the supplementary tables**.
Denominator	2,673 CRANE-registered children
What did we find? 	• 98% of CRANE-registered children had diagnosis time reported (Cleft Service range: 92%-100%, p<0.001). This compares to 97% for the previous reporting period (births 2021-2023). • Reporting varied significantly according to birth year (2022: 97%, 2023: 98%, 2024: 99%, p=0.017) and known cleft type (CL: 100%, CP:99%, UCLP: 99%, BCLP: 99%, SMCP+CL: 100%, SMCP: 92%, p<0.001). Only 78% of children with an 'unspecified' cleft type had diagnosis time reported. The reporting of diagnosis time did not vary significantly according to sex (female: 98%, male: 98%, p=0.325).
Outliers	Positive: None Negative: 1. West Midlands (91%)

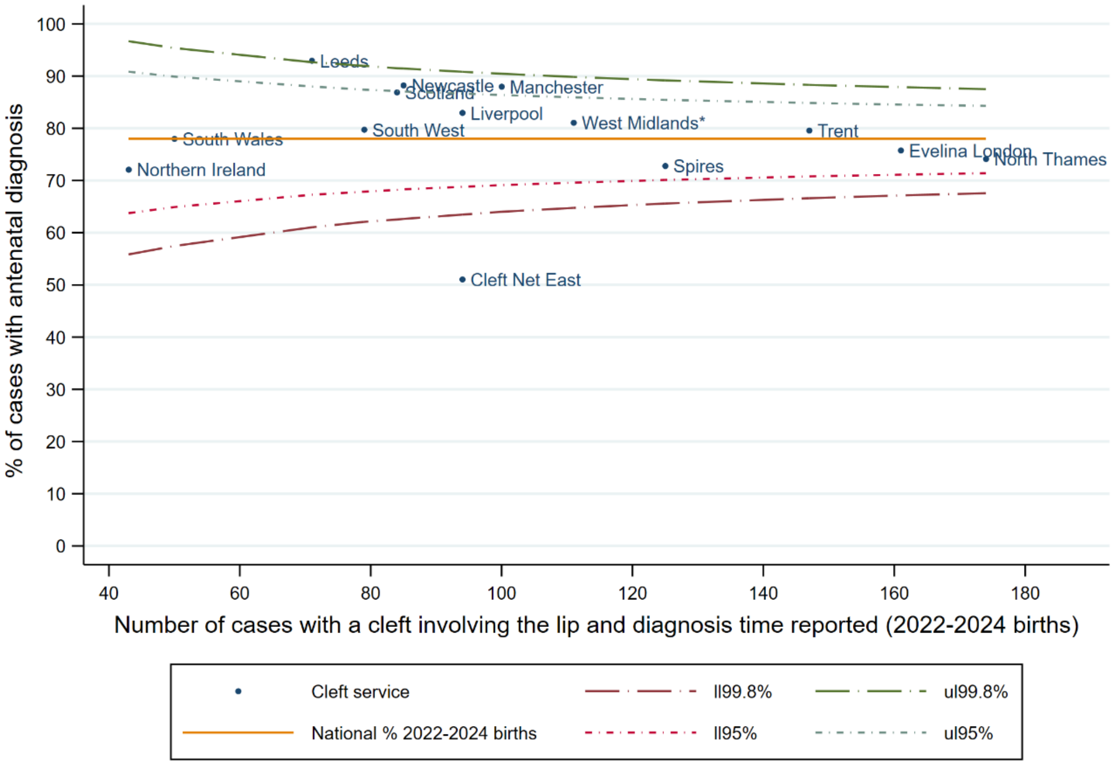
Figure 3.5. Funnel plot showing the percentage of all CRANE-registered children, born 2022 to 2024, who had diagnosis time reported, according to Cleft Service.



Note: Funnel plot centred on the national percentage (97.0%) of children (born 2022-2024) with diagnosis time reported.

Outcome: Timing of diagnosis among children with a cleft affecting the lip (CL, UCLP and BCLP)	
Indicator	#3 - Antenatal diagnosis for CL, UCLP and BCLP
Benchmark	Clefts involving the lip should be diagnosed antenatally. This was the case for 78% of children born 2021-2023.
Notes	• Outcome funnel plots are centred on the revised national rates after excluding data from services identified as negative outliers for timing of diagnosis data completeness (West Midlands). • Outcome data reflect care provided by maternity services referring on to Cleft Services.
Denominator	1,481 CRANE-registered children with a cleft affecting the lip and diagnosis time reported.
What did we find? 	• 78% of children with a cleft affecting the lip were diagnosed antenatally (Cleft Service range: 51%-93%, p<0.001). This rate remains unchanged compared to the previous reporting period (2021-2023 births). • Antenatal diagnosis rates varied significantly according to cleft type (CL: 69%, UCLP: 86%, BCLP: 86%, SMCP+CL: 69%, p<0.001), but not according to sex (p=0.149), ethnicity (p=0.109) or birth year (p=0.605).
Outliers	Positive: 1. Leeds (93%), 2. Manchester* (88%) Negative: 1. Cleft Net East (51%) * Positive alert status for two consecutive reporting periods and therefore classed as outlier.

Figure 3.6. Funnel plot showing the percentage of CRANE-registered children with a cleft affecting the lip, born 2022 to 2024, who had an antenatal diagnosis, according to Cleft Service.



Note: Funnel plot centred on the revised national percentage (78.0%) of children (born 2022-2024) with an antenatal diagnosis.

Outcome: Timing of diagnosis among children with a cleft palate alone	
Raw data	‘Diagnosis times CPO 2022-24’ in **the supplementary tables**.
Indicator	#4 - Timely detection of Cleft Palate (CP), within 24/72 hours from birth

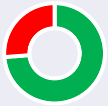
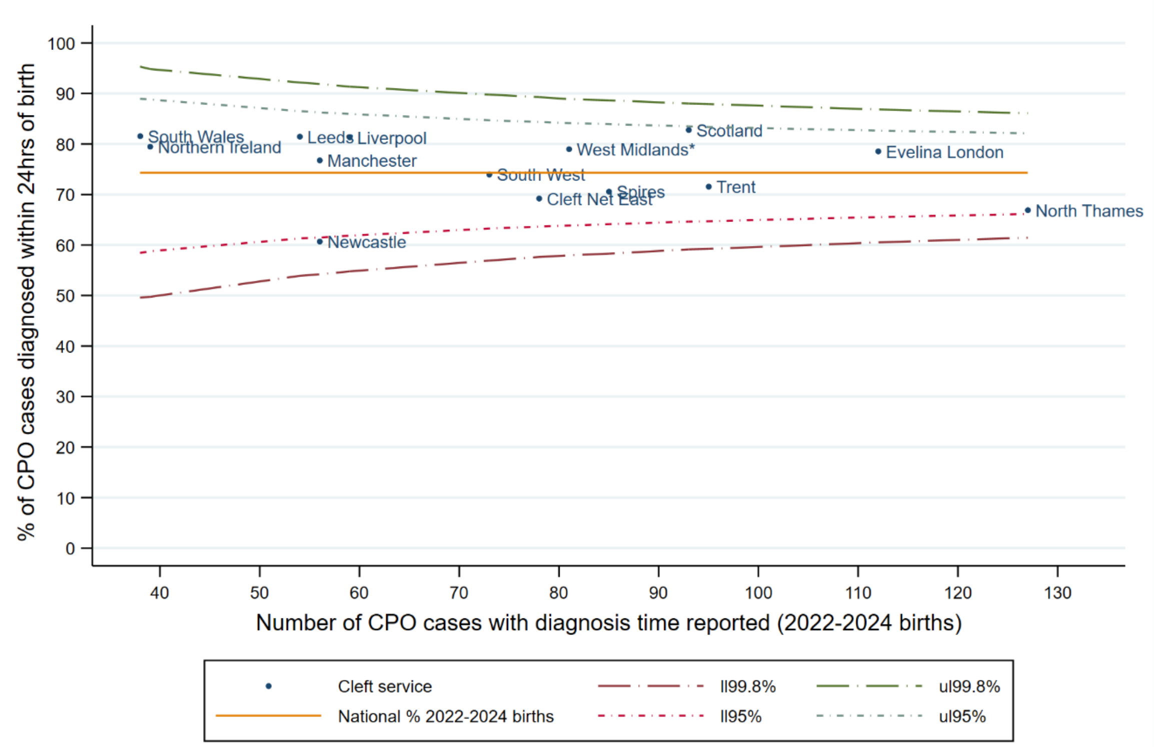
Benchmark	Clefts affecting only the palate should be diagnosed before or within 24 hours of birth. This was the case for 74% of children born 2021-2023. This increased to 84% when including diagnoses within 72 hours of birth, which is the timeframe recommended for the NIPE newborn screening examination[12].
Notes	• Outcome funnel plots are centred on the revised national rates after excluding data from services identified as negative outliers for timing of diagnosis data completeness (West Midlands). • Outcome data reflect care provided by maternity and neonatal services referring on to Cleft Services.
Exclusions	Children born <34 weeks are excluded from the timing of diagnosis outcome among children with cleft palate alone, as the newborn examination is appropriate only for babies born ≥34+0 weeks' gestation.
Denominator	• 1,046 children with a cleft affecting the palate alone (excluding SMCP) who were born ≥34 weeks' gestation and had diagnosis time reported. • 32 children with SMCP alone and diagnosis time reported.
Detection within 24 hours of birth	
What did we find? 	• 74% of children with a cleft affecting the palate alone (excluding SMCP) were diagnosed before or within 24 hours of birth (Cleft Service range: 61%-83%, p=0.064). This remains unchanged compared to the previous reporting period (births 2021-2023). • 24-hour diagnosis rates varied significantly according to extent of cleft involvement (LAHSAL codes 's': 54%, 'S': 72%, 'Sh': 74%, 'SH': 85%, p<0.001) and birth year (2022: 70%, 2023: 78%, 2024: 76%, p=0.036), but not by sex (p=0.478) or ethnicity (p=0.557). • 31% of children with a SMCP alone were diagnosed before or within 24 hours of birth. 16% were diagnosed 2-7 days after birth, 25% 7-28 days, 9% 1-6 months, and 19% >6 months after birth.
Outliers	None

Figure 3.7. Funnel plot showing the percentage of CRANE-registered children with a cleft affecting the palate alone (excluding SMCP), born ≥34 weeks' gestation from 2022 to 2024, who were diagnosed before or within 24 hours of birth, according to Cleft Service.



Note: Funnel plot centred on the revised national percentage (74.3%) of children (born 2022-24) diagnosed antenatally or <24 hours after birth.

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[12] Newborn and infant physical examination (NIPE) screening programme handbook - GOV.UK

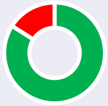
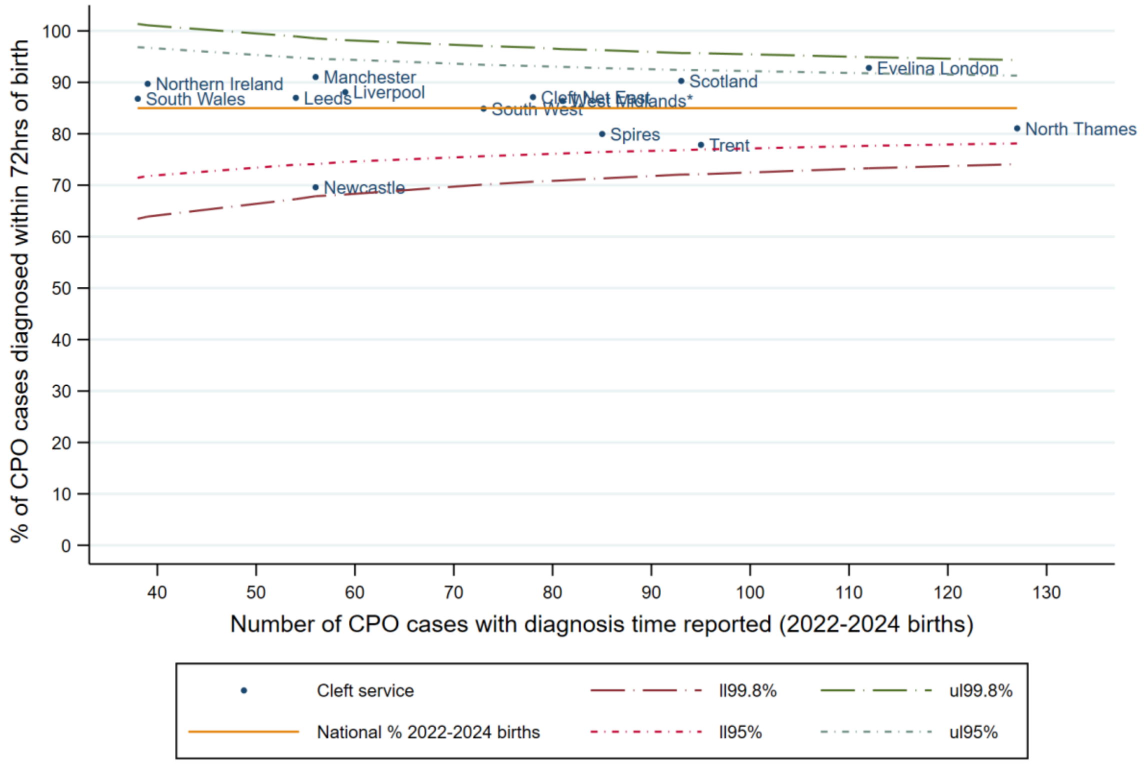
Detection within 72 hours of birth	
What did we find? 	• 85% of children with a cleft affecting the palate alone (excluding SMCP alone) were diagnosed before or within 72 hours of birth (Cleft Service range: 70%-93%, p=0.008). This represents minimal change compared to the previous reporting period (2021-2023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

Figure 3.8. Funnel plot showing the percentage of CRANE-registered children with a cleft affecting the palate alone (excluding SMCP), born ≥34 weeks' gestation from 2022 to 2024, who were diagnosed before or within 72 hours of birth, according to Cleft Service.



Note: Funnel plot centred on the revised national percentage (85.0%) of children (born 2022-24) diagnosed antenatally or <72 hours after birth.

3.3. Referral to and contact with Cleft Services

Early referral to Cleft Services ensures that children diagnosed with a cleft receive the care and support that they and their families need, in a timely fashion.

Recommendations: Referral and contact
• Cleft Services should record the referral and contact time for all registrations by working with referring obstetric, midwifery and neonatal units to improve the capture of this information. • Regional variation in the percentage of children referred, contacted and visited within 24 hours demonstrates that some Cleft Services have high levels of referrals and contacts within 24 hours. They should share their best practice recommendations with Cleft Services with lower rates.

3.3.1 Referral

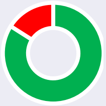
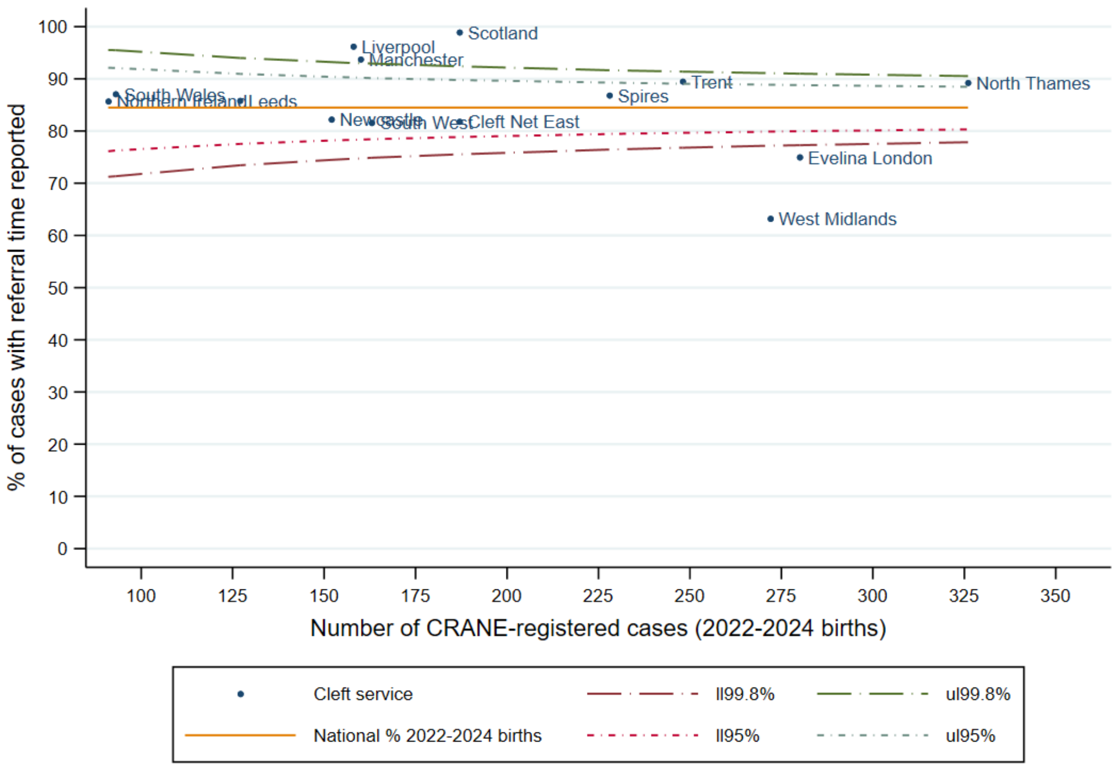
Data completeness: Postnatal referral time	
Raw data	'Referral 2022-24' in **the supplementary tables**.
Indicator	#5 - Referral recorded for all eligible children
Exclusions	Children who died before reaching 1 week of age[13]
Denominator	2,672 CRANE-registered children
What did we find? 	• 85% of all CRANE-registered children had a recorded postnatal referral time (Cleft Service range: 63%-99%, p<0.001). This compares to 82% for the previous reporting period (births 2021-2023). • The percentage of children with a recorded referral time varied significantly according to birth year (2022: 85%, 2023: 87%, 2024: 82%, p=0.025), cleft type (CL: 86%, CP: 86%, UCLP: 89%, BCLP: 88%, SMCP+CL: 94%, SMCP: 58%, p<0.001) and ethnicity (white: 89%, ethnic minority groups: 82%, p<0.001, but not according to sex (p=0.607).
Outliers	Positive: 1. Scotland (99%), 2. Liverpool (96%), 3. Manchester (94%) Negative: 1. West Midlands (63%), 2. Evelina London (75%)

Figure 3.9. Funnel plot showing the percentage of CRANE-registered children, born 2022 to 2024, who had postnatal referral time reported, according to Cleft Service.



Note: Funnel plot centred on the national percentage (84.5%) of children (born 2022-2024) with referral time reported.

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[13] Children dying within the first 6 days of life within this cohort are excluded as referral may not be appropriate.

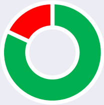
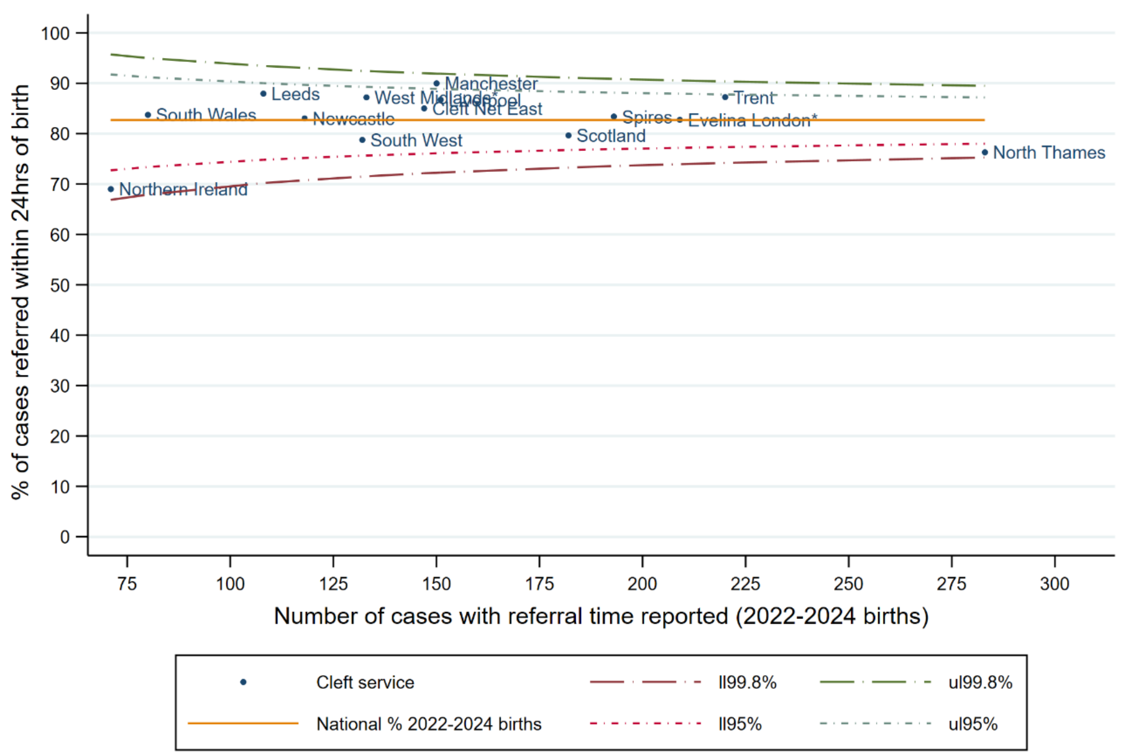
Outcome: Referral to Cleft Service within 24 hours of birth	
Indicator	#6 - Referral to a Cleft Service within 24 hours of birth
Benchmarks	82% of children born with a cleft in 2020-2022 were referred to Cleft Services within 24 hours of birth (CRANE, 2023).
Notes	As the percentage of CRANE-registered children with SMCP alone and unspecified cleft types vary between Cleft Services and that referral within 24hrs of birth is significantly lower among these children too, these children have been excluded from the rates presented in the funnel plot below.
Denominator	2,259 CRANE-registered cases with referral time recorded
What did we find? 	• 82% of children were referred to a Cleft Service within 24hrs of birth (Cleft Service range: 64%-90%, p<0.001). This remains unchanged from the previous reporting period (2021-2023 births). • Referrals within 24hrs of birth varied according to birth year (2022: 85%, 2023: 87%, 2024: 82%, p=0.025), cleft type (CL: 91%, CP: 69%, UCLP: 96%, BCLP: 96%, SMCP+CL: 73%, SMCP:23%, p<0.001) and sex (female: 80%, male: 84%, p=0.048). These findings are consistent with later diagnosis times for children with SMCP and CP, with the latter more prevalent among females. • 60% of referrals occurring beyond 24 hours after birth (in those born ≥34 weeks) were explained by later diagnosis times, while 40% had a timely diagnosis. • When excluding from analyses children with SMCP alone or an unspecified cleft type, the overall referral rate within 24hrs of birth increased to 83% (Cleft Service range: 69%-90%, p<0.001).
Outliers	Positive: 1. Manchester* (90%) Negative: 1. North Thames* (76%) *Alert status for two consecutive reporting periods and therefore classed as outlier.

Figure 3.10. Funnel plot showing the percentage of CRANE-registered children, born 2022 to 2024, who had been referred to a Cleft Service within 24hrs of birth, according to Cleft Service. Excludes children with an SMCP alone and those with an unspecified cleft type.

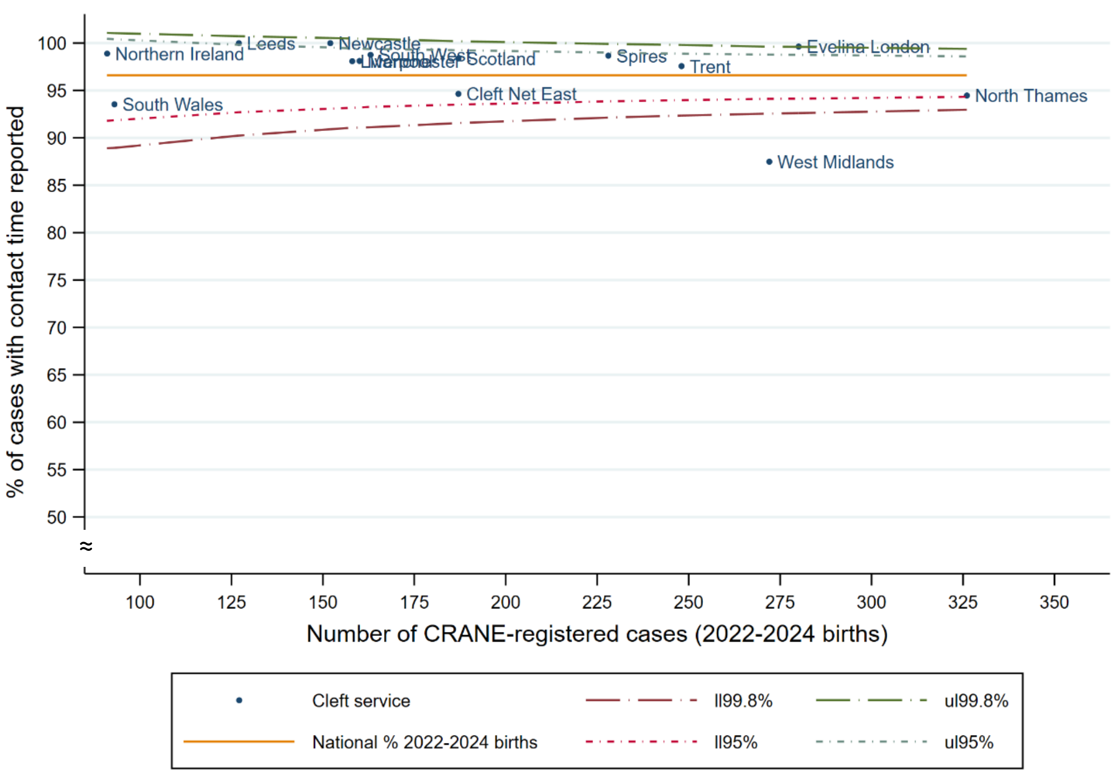


Note: Funnel plot centred on the revised national percentage (82.7%) of children (born 2022-2024) referred within 24hrs of birth.

3.3.2 Contact

Data completeness: Contact time between Cleft Service and family after postnatal referral	
Raw data	‘Contact & visit 2022-24’ in **the supplementary tables**.
Indicator	#7 – Contact time between Cleft Service and family recorded for all eligible children
Exclusions	Children who died before reaching 1 week of age[14]
Denominator	2,672 CRANE-registered children, including 1,120 children with antenatal diagnosis.
What did we find? 	• 97% of all CRANE-registered children had a recorded contact time (Cleft Service range: 88%-100%, $p<0.001$). This compares to 95% for the previous reporting period (births 2021-2023). • The reporting of contact time varied significantly according to cleft type (CL:98%, CP: 99%, UCLP: 98%, BCLP: 97%, SMCP+CL:100%, SMCP: 89%, $p=0.001$), but not by sex ($p=0.360$), ethnicity ($p=0.320$) or birth year ($p=0.248$).
Outliers	Positive: 1. Newcastle* (100%), 2. Evelina London (100%) Negative: 1. West Midlands (88%) * Positive alert status for two consecutive reporting periods and therefore classed as outlier.

Figure 3.11. Funnel plot showing the percentage of CRANE-registered children, born 2022 to 2024, who had contact time between Cleft Service and family reported, according to Cleft Service.



Note: Funnel plot centred on the national percentage (96.6%) of children (born 2022-2024) with contact time reported.

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[14] Children dying within the first 6 days of life within this cohort are excluded as referral may not be appropriate.

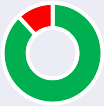
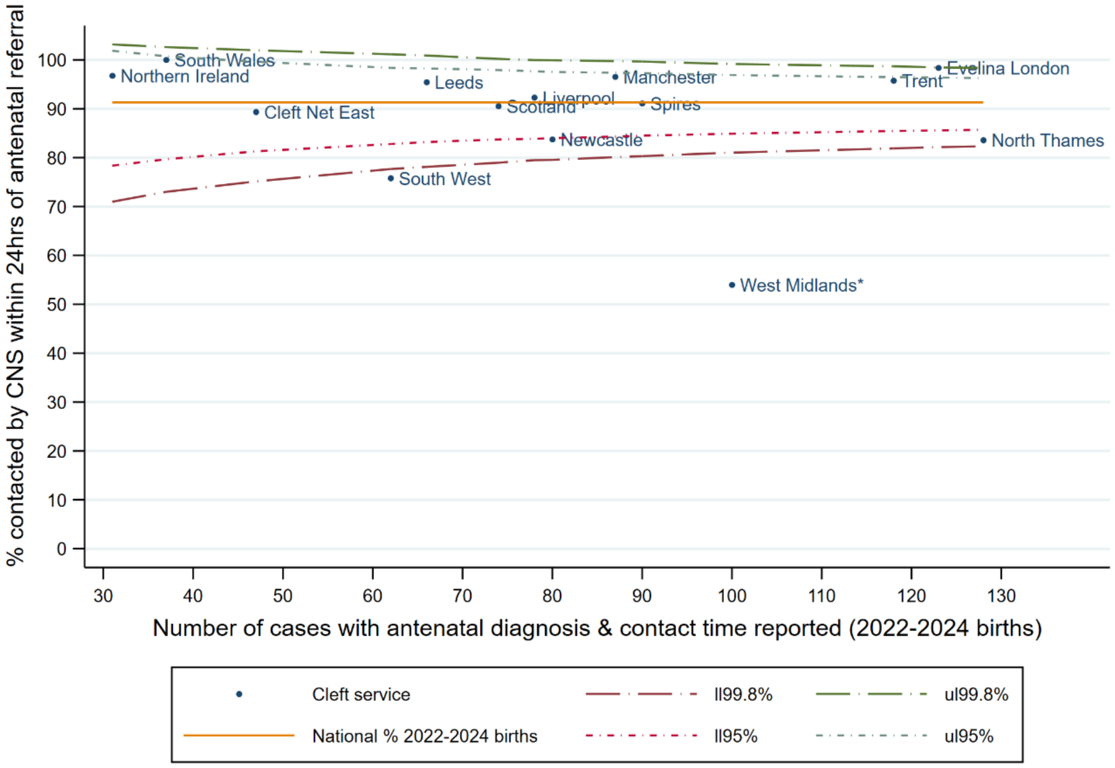
Outcome: Contact between Cleft Service and family within 24 hours of antenatal referral	
Indicator	#8a - Contact between Cleft Service and family within 24 hours of antenatal referral
Benchmarks	Families should be contacted by the Clinical Nurse Specialist within 24 hours of antenatal referral.
Denominator	1,121 CRANE-registered cases with antenatal diagnosis and contact time reported
What did we find? 	• 88% of children were contacted by the Clinical Nurse Specialist (CNS) within 24hrs of the service receiving an antenatal referral (Cleft Service range: 54%-100%, p<0.001). This has not changed compared to 2021-2023 births. • The percentage of families receiving contact within 24hrs of antenatal referral varied by ethnicity (white: 92%, ethnic minority groups: 86%, p=0.020), but not by cleft type (p=0.859), sex (p=0.746) or birth year (p=0.532).
Outliers	Positive: None Negative: 1. West Midlands (54%), 2. South West (76%)

Figure 3.12. Funnel plot showing the percentage of CRANE-registered children, born 2022 to 2024, who had been contacted by a Clinical Nurse Specialist (CNS) within 24hrs of antenatal referral, according to Cleft Service.



Note: Funnel plot centred on the revised national percentage (91.3%) of children (born 2022-2024) contacted by CNS within 24hrs of antenatal referral.

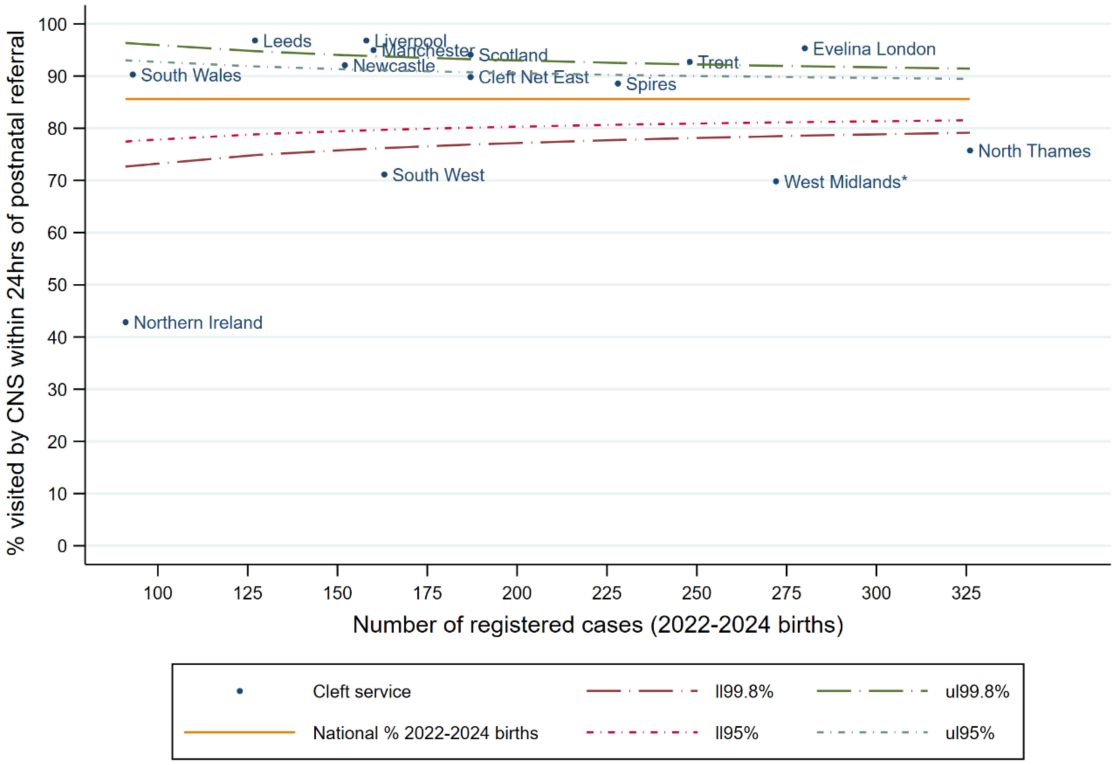
Outcome: Contact between Cleft Service and family within 24 hours of postnatal referral	
Indicator	#8b - Contact between Cleft Service and family within 24 hours of postnatal referral
Benchmarks	94% of children born with a cleft in 2021-2023 were contacted by their Cleft Service within 24 hours of the service receiving their postnatal referral (CRANE, 2024).
Denominator	2,450 CRANE-registered cases with postnatal contact time reported
What did we find? 	• 95% of children were contacted by their Cleft Service within 24hrs of the service receiving a postnatal referral (Cleft Service range: 83%-100%, p<0.001). This is similar to the previous reporting period (2021-2023 births). • The percentage of families receiving contact within 24hrs of referral varied significantly by cleft type (CL: 96%, CP: 95%, UCLP:96%, BCLP: 96%, SMCP:+CL: 88%, SMCP:74%, p<0.001), but not by sex (p=0.703), ethnicity (p=0.820) or birth year (p=0.055). • Excluding cases with a submucous cleft palate alone did not change the outlier status of services.
Outliers	Positive: 1. Trent (100%), Manchester* (100%) Negative: 1. Northern Ireland (83%), 2. West Midlands (84%), 3. North Thames (92%) *Same alert status for two consecutive reporting periods and therefore classed as outlier.

Figure 3.13. Funnel plot showing the percentage of CRANE-registered children, born 2022 to 2024, who had been contacted by a Cleft Service within 24hrs of postnatal referral, according to Cleft Service.

Note: Funnel plot centred on the revised national percentage (96.0%) of children (born 2022-2024) contacted within 24hrs of referral.

Outcome: Family visited by Clinical Nurse Specialist within 24 hours of postnatal referral	
Indicator	#8c– Visit by Clinical Nurse Specialist (CNS) within 24 hours of postnatal referral
Benchmarks	84% of children born with a cleft in 2021-2023 were visited by a CNS within 24 hours of the service receiving their referral (CRANE, 2024).
Denominator	2,672 CRANE-registered cases
What did we find?	• 86% of children were visited by the cleft team within 24hrs of the service receiving a postnatal referral (Cleft Service range: 46%-98%, p<0.001). 99% of visits were by the CNS. • The percentage of families visited by a CNS within 24hrs of postnatal referral varied significantly by known cleft type (CL: 90%, CP: 86%, UCLP: 91%, BCLP: 89%, SMCP+CL:50%, SMCP: 50%, p<0.001), but not by birth year (p=0.132), sex (p=0.862) or ethnicity (p-0.399). • Excluding cases with a submucous cleft palate alone did not change the outlier status of services. • Reasons for not visiting within 24 hours of postnatal referral were wide-ranging, with ‘other’ and free text responses given for 41% of cases. Additional reasons included: Clinical decision based on the presence of other comorbidities: 15%, Clinical decision based on the baby feeding well and no concerns: 9%, No CNS available: 10%, and Travel distance (1%).
Outliers	Positive: 1. Leeds (97%), 2. Liverpool (97%), 3. Evelina London (95%), 4. Scotland (94%), 5. Trent (93%), 6. Newcastle* (92%) Negative: 1. Northern Ireland (43%), 2. West Midlands (70%), 3. South West (71%), 4. North Thames (76%) *Positive alert status for two consecutive reporting periods and therefore classed as outlier.

Figure 3.14. Funnel plot showing the percentage of CRANE-registered children, born 2022 to 2024, who were visited by a Clinical Nurse Specialist within 24hrs of postnatal referral, according to Cleft Service.



Note: Funnel plot centred on the national percentage (85.6%) of children (born 2022-2024) visited by a CNS within 24hrs of postnatal referral.

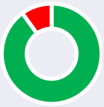
4. Consent

Cleft Services are responsible for approaching the families of all children born alive with a cleft to obtain consent for CRANE to collect outcome data. This section reports the consent status of children born 2022-2024, reflecting recent registrations, and 2016-2018, reflecting registrations of children who should have undergone their 5-year-old assessment of cleft-related outcomes. Consent verification is a key performance indicator and denotes a confirmed consent status, whereby families have either given informed consent or declined consent for CRANE to collect outcome data. In accordance with our Outlier Policy[15], data from any service identified as a negative outlier for consent verification will be excluded from revised totals and averages used to generate funnel plots of outcomes collected for consented children only. This ensures that results reflect patient populations only from services with acceptable levels of consent verification.

Recommendations: Consent
• Cleft Services with high consent rates should share their best practice recommendations. • Cleft Services with below average consent rates should review their procedures to identify opportunities to make improvements.

Cohort summary	
Data source	The CRANE Database. Extract taken: 30 June 2025
Countries	England, Wales, Northern Ireland and Scotland
Inclusions	CRANE-registered children
Notes	Data are not risk adjusted

4.1. CRANE consent, 2022-2024 births

Outcome: Consent status	
Raw data	• 'Consent 2022-24' in **the supplementary tables**.
Indicator	• #9 - Consent status verified for all CRANE-registered children.
Benchmarks	• 100% of CRANE-registered children should have their consent status verified (informed consent given or declined) regarding CRANE outcome data collection. • 88% of children born 2021-2023 had a verified consent status (CRANE, 2024).
Birth years	• Three years: 2022 to 2024
Notes	• Consent verification is not subject to outlier policy for recent birth years
Exclusions	• Children who died • Children with submucous cleft palate alone[16]
Denominator	2,600 (2,594 CRANE-registered children + 6 non-consented/registered children in Scotland)
What did we find? 	• 90% of eligible children had a verified consent status (Cleft Service range: 71%-100%, $p<0.001$). This rate increased by 2% compared to the previous reporting period (births 2021-2023). • Consent verification varied significantly according to birth year (2022: 91%, 2023: 94%, 2024: 86%, $p<0.001$), but not by known cleft type ($p=0.103$), sex ($p=0.943$) or ethnicity ($p=0.192$). • 88% had provided informed consent to outcome data collection in CRANE. Among those with verified consent status, 97% gave consent (Cleft Service range: 90%-99.5%, $p<0.001$). Positive consent varied by

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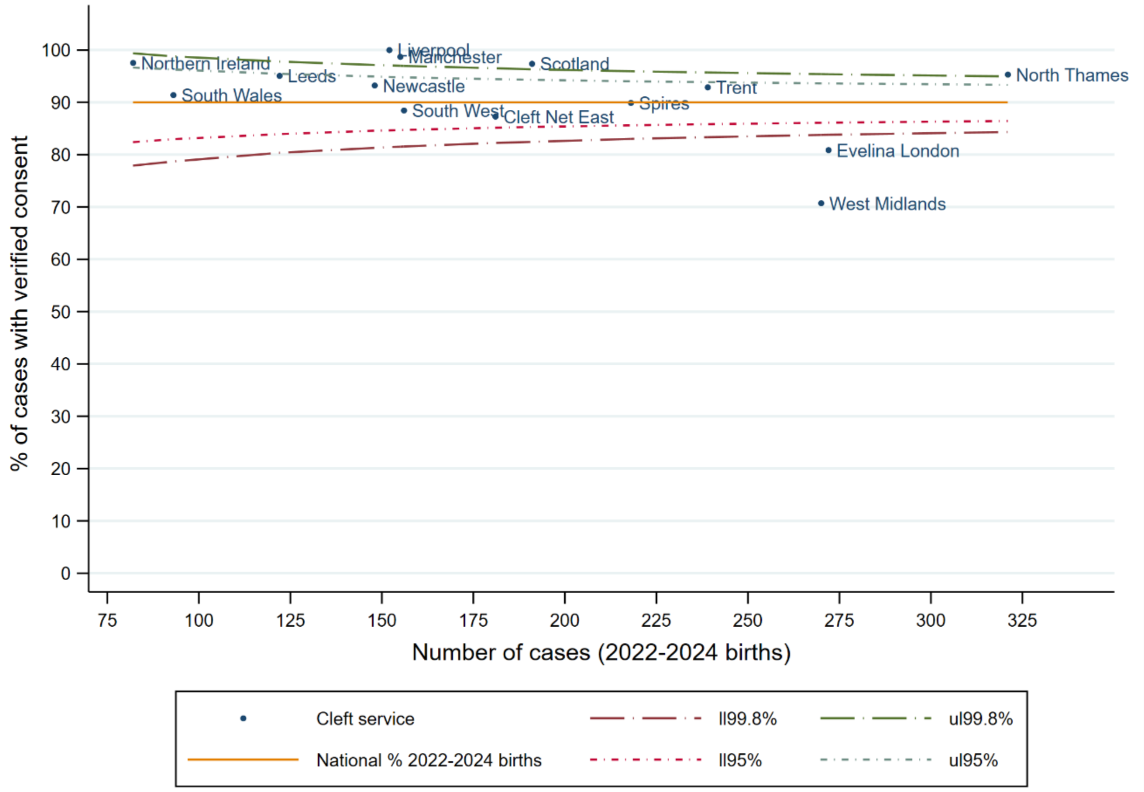
[15] CRANE Outlier Policy.

[16] Patients with submucous cleft palate alone are excluded from outcomes.

	birth year (2022: 98%, 2023: 96%, 2024: 98%, p=0.008) and ethnicity (white: 97%, ethnic minority groups: 95%, p=0.033), but not by cleft type (p=0.715) or sex (0.94). • <3% declined consent. • 10% were awaiting consent verification. • <1% were not possible to verify. • Of those with consent, 99% also consented to linkage of CRANE data with health and education data.
Outliers	Positive: 1. Liverpool (100%), 2. Manchester (99%), 3. Scotland (97%), 4. North Thames (95%) Negative: 1. West Midlands (71%), 2. Evelina London (81%)

Figure 4.1. Funnel plot showing the percentage of CRANE-registered children, born 2022 to 2024, who had verified consent status, according to Cleft Service.



4.2. CRANE consent, 2016-2018 births

Outcome: Consent status	
Raw data	‘Consent 2016-18’ in **the supplementary tables**.
Indicator	#9 - Consent verification status verified for all CRANE-registered children
Benchmarks	• 100% of CRANE-registered children should have their consent status verified (informed consent given or declined) regarding CRANE outcome data collection. • 91% of 5-year-old children born 2015-2017 had a verified consent status (CRANE, 2024).
Birth years	• Birth years
Exclusions	• Children who died before the age of 5 years • Children with submucous cleft palate[17] • Children who transferred cleft care between 2 months and 5 years of age

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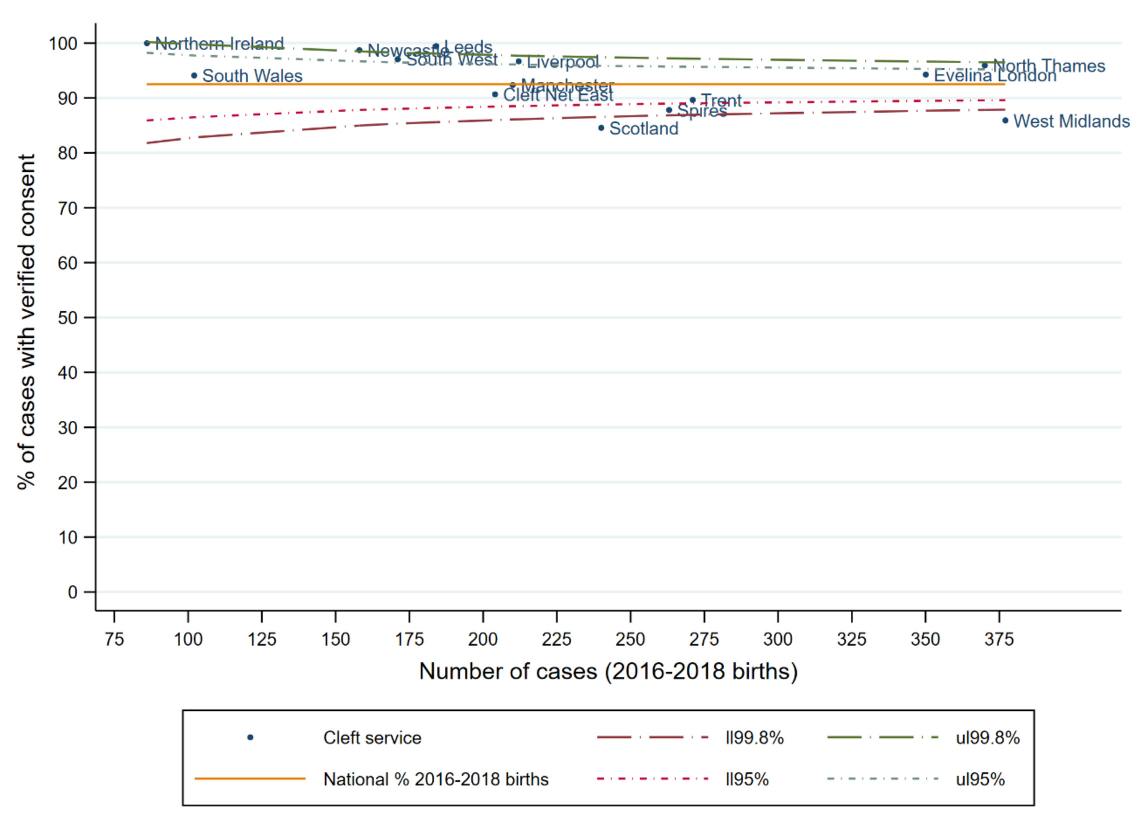
[17] Patients with submucous cleft palate alone are excluded from outcomes.

Notes	• Subject to outlier policy. • Data are not risk adjusted. • Scotland joined CRANE in 2023 and has retrospectively entered data for 2016-2018 births to be included in analyses. Legally, Scotland can only register on CRANE consented cases, and they therefore must provide us with their denominator separately.
Denominator	3,189 (3,150 CRANE-registered children + 39 non-consented/registered children in Scotland)
What did we find? 	• 92% of eligible children had a verified consent status (Cleft Service range: 85%-100%, p<0.001). This rate is similar to the previous reporting period (2015-2017 births). • Consent verification varied significantly according to known cleft type (CL: 91%, CP: 94%, UCLP: 97%, BCLP: 97%, p<0.001), but not by sex (p=0.759), ethnicity (p=0.210) or birth year (p=0.943). • 90% had provided informed consent to outcome data collection in CRANE. Among those with verified consent status, 97% gave consent (Cleft Service range: 94%-100%, p<0.001). • <3% declined consent. • 6% were awaiting consent verification. • <2% were not possible to verify.
Outliers	Positive: 1. Northern Ireland* (100%), 2. Leeds (100%), 3. Newcastle (99%), 4. North Thames* (96%) Negative: 1. Scotland (85%), 2. West Midlands (86%) *Positive alert for two consecutive reporting periods and therefore classed as outlier.

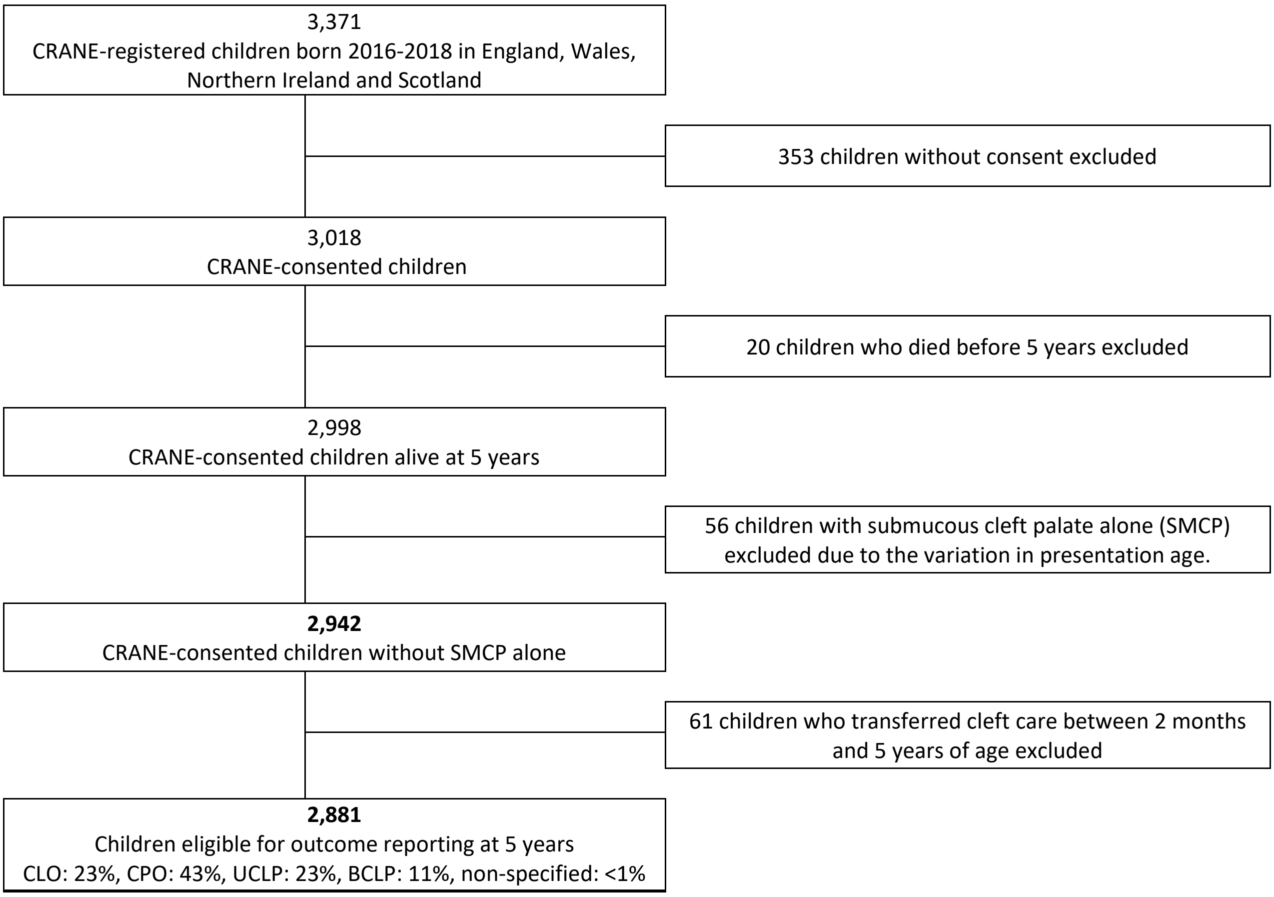
Figure 4.2. Funnel plot showing the percentage of CRANE-registered 5-year-olds, born 2016 to 2018, who had verified consent status, according to Cleft Service.



5. Audit outcomes at 5 years of age

This chapter presents cleft-related 5-year outcomes for CRANE-consented children, born 2016 to 2018.

Figure 5.1. CRANE cohort eligible for 5-year outcome reporting.



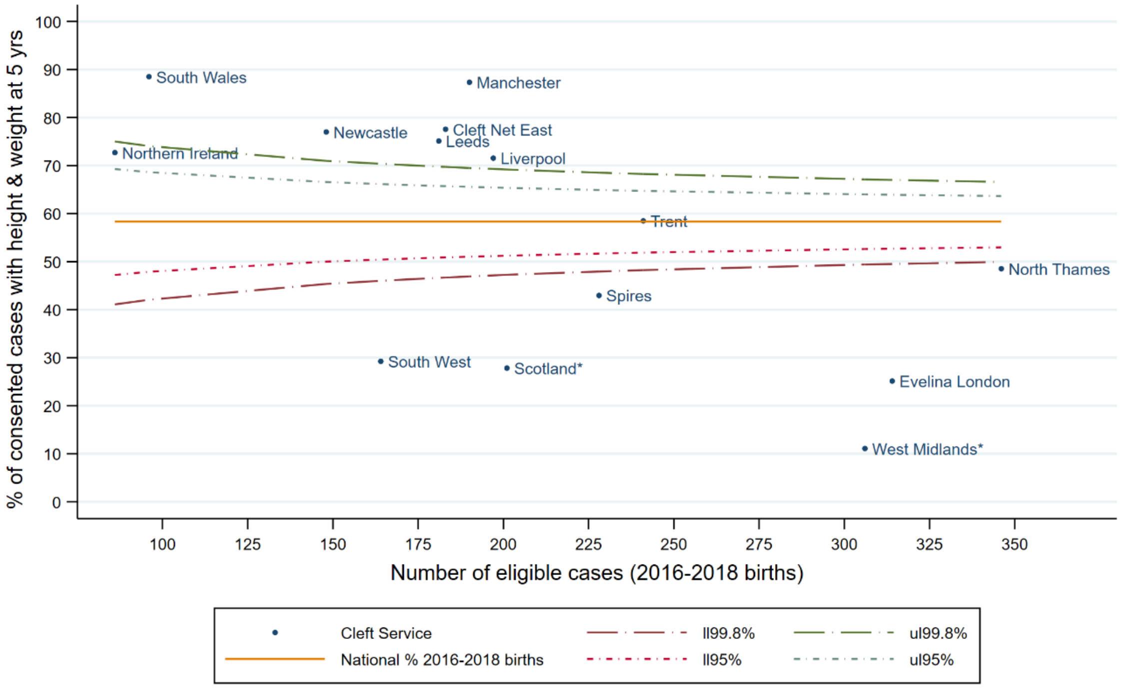
Cohort summary	
Data source	The CRANE Database. Extract taken: 30 June 2025
Birth years	Three years: 2016 to 2018
Countries	England, Wales, Northern Ireland and Scotland
Inclusions	CRANE-consented children, including those without a specified cleft type, unless stated otherwise
Exclusions	• Children who died before the age of 5 years • Children with submucous cleft palate alone • Children who transferred cleft care between 2 months and 5 years of age
Notes	• Subject to outlier policy • Data are risk adjusted for dental dmft data and speech outcomes only • All funnel plots are centred on the revised national rates after excluding data from services identified as negative outliers for consent verification (Scotland and West Midlands). • Outcome funnel plots are centred on the revised national rates after additionally excluding data from services identified as negative outliers for the relevant data completeness indicator. • Cleft Services with <10 cases are not shown on funnel plot due to insufficient data
Legal basis for data collection	The data used for this section are collected for all children whose families have given informed consent to outcomes data collection by the CRANE Database.

5.1. Child growth

Recommendations: Child growth
• Cleft Services should aim to assess children’s weight and height at age 5 and improve the reporting of these measures in the CRANE Database. This will facilitate more meaningful comparisons between cleft subtypes in the future. • CRANE will continue to liaise with CDG members and the nursing CEN to encourage all services to collect this data. • Research should explore reasons why the BMI distribution differs between the cleft and general population of 5-year-olds.

Data completeness: Height and weight	
Raw data	‘Child growth 2016-18’ in **the supplementary tables**
Indicator	#10 - Child growth at 5 years recorded for all eligible children
Denominator	2,881 CRANE-consented children
What did we find?	• 51% of eligible consented children had a recorded height and weight (Cleft Service range: 11%-89%, p<0.001). This rate compares to 38% for the previous reporting period (births 2015-2017). • <1% of children only had a recorded height. • 1% of children only had a recorded weight. • 25% had a reason the child growth outcomes were not collected. • 23% were missing data and a reason for not collecting data. • The proportion of children with height and weight measures varied significantly according to birth year (2016: 42%, 2017: 52%, 2018: 60%, p<0.001) and by cleft type (CL: 46%, CP:50%, UCLP:54%, BCLP: 60%, p<0.001), but not by sex (p=0.231) or ethnicity (p=0.06).
Outliers	Positive: 1. South Wales (89%), 2. Manchester (87%), 3. Cleft Net East (78%), 4. Newcastle (77%), 5. Leeds (75%), 6. Liverpool (72%) Negative: 1. West Midlands (11%), 2. Evelina London (25%), 3. Scotland (28%), 4. South West (29%), 5. Spires (43%), 6. North Thames (49%)

Figure 5.2. Funnel plot showing the percentage of CRANE-consented 5-year-olds, born 2016 to 2018, with growth data reported, according to Cleft Service.



Note: Funnel plot centred on the revised national percentage (58.3%) of children (born 2016-2018) with child growth outcomes reported.

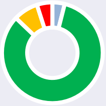
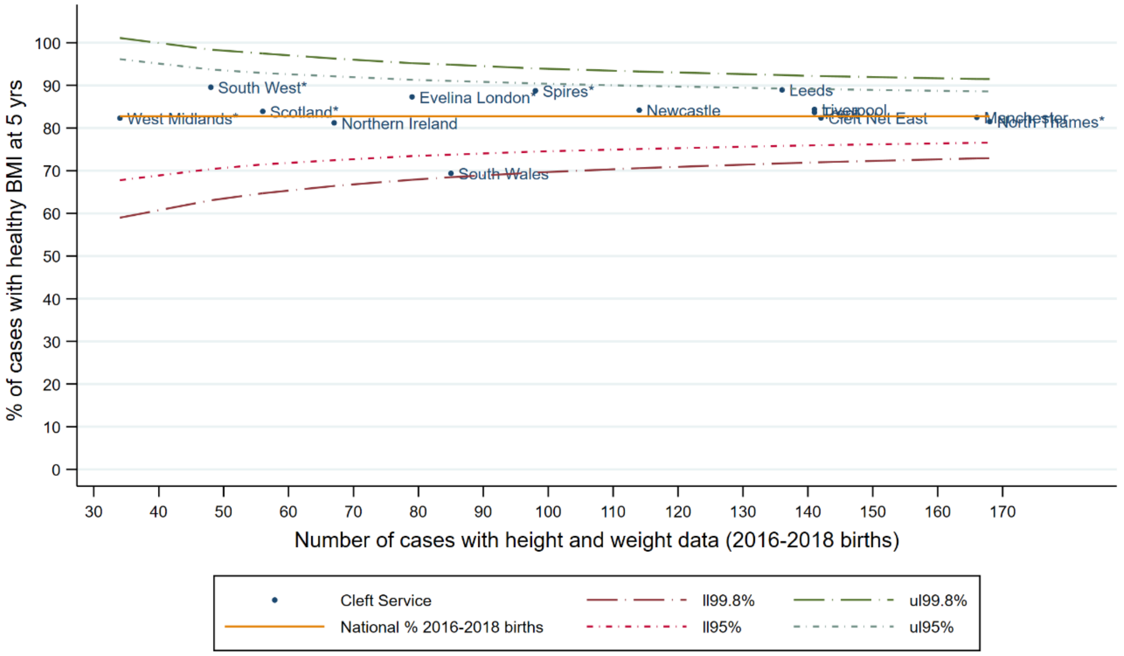
Outcome: Healthy BMI	
Indicator	#11 - Healthy Body Mass Index (BMI) at 5 years of age.
Benchmarks	• Prevalence of underweight, healthy weight, overweight and obesity among 5-year-olds in the general population is estimated at 1%, 77%, 12% and 10%, respectively[18]. • 83% of eligible children born 2015-2017 were reported to have a healthy BMI (CRANE, 2024).
Notes	• Body mass index (BMI) at 5 years of age was calculated as weight (kg)/height (m)^2. • For 5-year-olds in the UK[19], underweight is BMI <13.0 kg/m2, healthy BMI 13.0-17.5 (2nd to 91st centiles), overweight is BMI 17.5-19.0 kg/m2 (92nd to 98th centiles), and obese is BMI >19.0 kg/m^2. • Funnel plot is centred on the revised national rate after excluding data from services identified as negative outliers for consent verification (Scotland and West Midlands) and child growth data completeness (West Midlands, North Thames, Spires, Evelina London, South West and Scotland).
Denominator	1,475 CRANE-consented children with a recorded height and weight
What did we find? 	• Average weight, height and BMI for those with reported data was 20.1kg (95% CI 20.0-20.3kg), 113.2cm (95% CI 112.9-113.5cm) and 15.7 kg/m^2 (95% CI: 15.6 kg/m^2 to 15.7 kg/m^2), respectively. • 84% of children had a healthy BMI (Cleft Service range: 69%[20] to 90%[21], p=0.081). This represents minimal change from the previous reporting period and is higher than the 77% reported for the general population. • 4% of children were underweight, 8% overweight and 5% obese. • The proportion of children within each BMI category varied significantly according to sex (female: underweight: 6%, healthy weight:80%, overweight: 10%, obese: 5%; Male: underweight: 2%, healthy weight: 86%, overweight: 7%, obese: 5%, p<0.001), but not by cleft type (p=0.210), ethnicity (p=0.227) or birth year (p=0.535).
Outliers	None.

Figure 5.3. Funnel plot showing the percentage of CRANE-consented 5-year-olds, born 2016 to 2018, with a healthy BMI, according to Cleft Service.



Note: Funnel plot centred on the revised national percentage (82.8%) of children (born 2016-2018) with a healthy BMI.

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[18] National Child Measurement Programme Tables, England 2021/22 and 2022/23 School Years [Last accessed: 12/07/2024]

[19] Royal College of Paediatrics and Child Health and UK-WHO growth charts – 2-18 years [Last accessed: 12/12/2022]

[20] As part of the outlier process, South Wales investigated their underweight cases due to their position on the funnel plot. Their outlier response revealed that some of their cases had an inaccurate height measurement, resulting in an underestimated BMI. When excluding BMI measures from South Wales, the national proportion of children classed as being underweight, healthy, overweight and obese is 3%, 84%, 8% and 4%, respectively.

[21] Note that Scotland (96%) were a negative outlier for consent verification and child growth data completeness so interpret this rate with caution. The highest rate among services not identified as negative outliers for consent or data completion was 90% (Leeds).

5.2. Dental health

5-year-old children with all cleft types are eligible for an assessment of their dental health and have this recorded as a decayed, missing or filled teeth (dmft) score. A dmft score is a measure of oral health and reflects the total number of teeth that are decayed, missing or filled. A dmft >0 indicates experience of dental decay and dmft >5 indicates experience of extensive dental decay. The risk of dental caries is thought to be higher among children with a cleft lip and/or palate compared with children without an oral cleft[22].

Recommendations: Dental health
• Cleft Services should have at least 80% of all children with a cleft assessed at the age of 5 years by a calibrated specialist in paediatric dentistry, in line with paediatric dentistry CEN standards, and the dmft and dental anomalies information should be recorded in the CRANE Database. • All children with a cleft should have a recommended care plan established by collaborative work between the family's local dental care provider and the specialist paediatric dentist in the Cleft Service. This should (a) treat the child as per the high-risk category of the dental health toolkit (Delivering Better Oral Health), (b) provide routine dental care within the general dental service, and (c) provide specialist level care including age-specific dental development assessment and treatment under inhalation sedation and general anaesthesia within the Cleft Service. • The COVID-19 pandemic had a significant impact on access to dental care in the early years for this population of patients, particularly those from more deprived areas[23]. Anecdotal and local evidence suggests that access to NHS dental care has still not recovered to pre-pandemic levels particularly in some regions of the country. All children with a cleft should have access to a local NHS dental provider by their 1st birthday to instigate early preventive advice and build a positive dental relationship.

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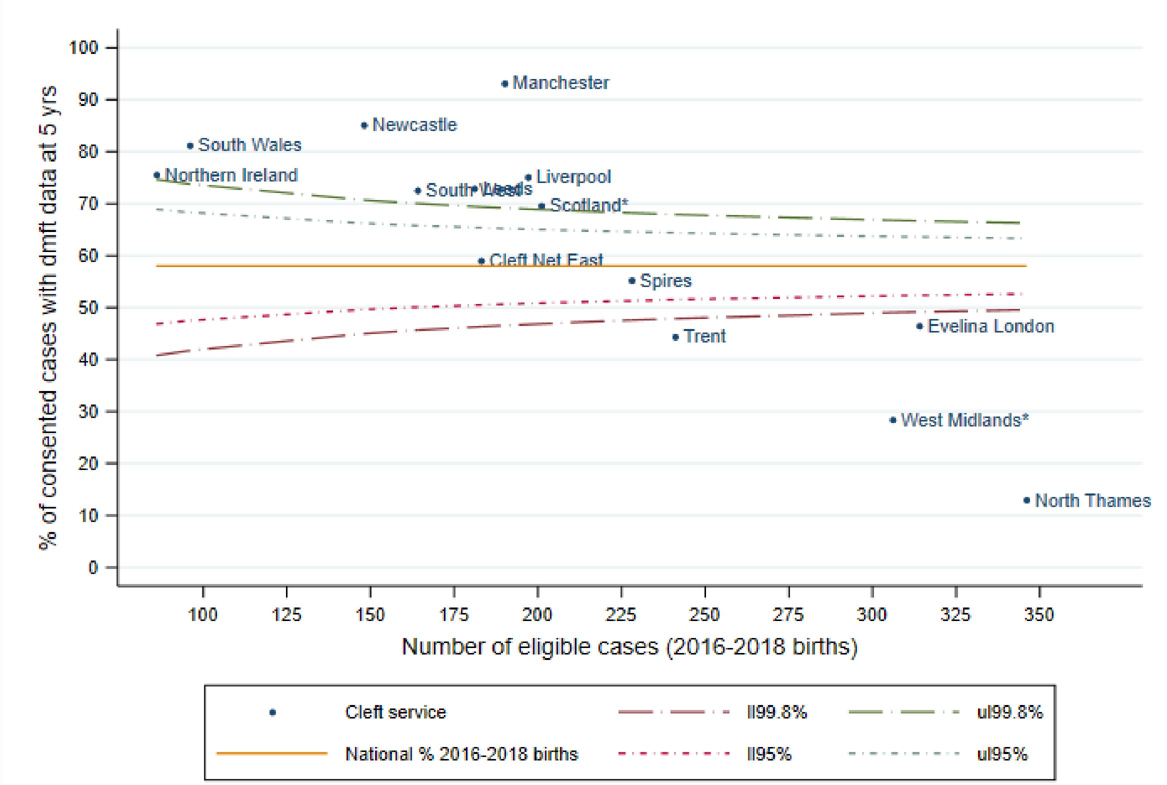
[22] (1) Al-Dajani. Comparison of dental caries prevalence in patients with cleft lip and/or palate and their sibling controls. The Cleft Palate-Craniofacial Journal, 2009. 46(5):529-531. (2) Britton and Welbury, Dental caries prevalence in children with cleft lip/palate aged between 6 months and 6 years in the West of Scotland. European Archives of Paediatric Dentistry, 2010.11(5):236-241.

[23] Aminu AQ, McMahon AD, Clark C, Sherriff A, Buchanan C, Watling C, Mahmoud A, Culshaw S, Mackay W, Gorman M, Braid R, Edwards M, Conway DI. Inequalities in access to NHS primary care dental services in Scotland during the COVID-19 pandemic. Br Dent J. 2023 May 24:1–6. doi: 10.1038/s41415-023-5856-z. Epub ahead of print. PMID: 37225842; PMCID: PMC10208681.
O´Connor, R., Landes, D. & Harris, R. Trends and inequalities in realised access to NHS primary care dental services in England before, during and throughout recovery from the COVID-19 pandemic. Br Dent J (2023). https://doi.org/10.1038/s41415-023-6032-1
Stennett, M., Tsakos, G. The impact of the COVID-19 pandemic on oral health inequalities and access to oral healthcare in England. Br Dent J 232, 109–114 (2022). https://doi.org/10.1038/s41415-021-3718-0

Data completeness: dmft scores	
Raw data	‘Dental health 2016-18’ in **the supplementary tables**
Indicators	#12 – dmft at 5 years recorded for all eligible children
Denominator	2,881 CRANE-consented children
What did we find? 	• 56% of eligible consented children had recorded dmft scores (Cleft Service range: 13%-93%, p<0.001). This rate compares to 45% for the previous reporting period (births 2016-2018). • 21% had a reason dmft scores were not collected. • 23% were missing data and a reason for not collecting data. • The proportion of children with dmft scores varied significantly according to birth year (2016: 47%, 2017: 57%, 2018: 63%, p<0.001), cleft type (CL: 51%, CP: 55%, UCLP: 61%, BCLP: 58%, p=0.004) and ethnicity (white: 74%, ethnic minority groups: 79%, p=0.04), but not by sex (p=0.261).
Outliers	Positive: 1. Manchester (93%), 2. Newcastle (85%), 3. South Wales (81%), 4. Northern Ireland (76%), 5. Liverpool (75%), 6. Leeds (73%), 7. South West (73%), 8. Scotland (70%) Negative: 1. North Thames (13%), 2. West Midlands (28%), 3. Trent (44%), 4. Evelina London (47%)

Figure 5.4. Funnel plot showing the percentage of CRANE-consented 5-year-olds, born 2016 to 2018, who had decayed, missing or filled teeth (dmft) scores reported, according to Cleft Service.

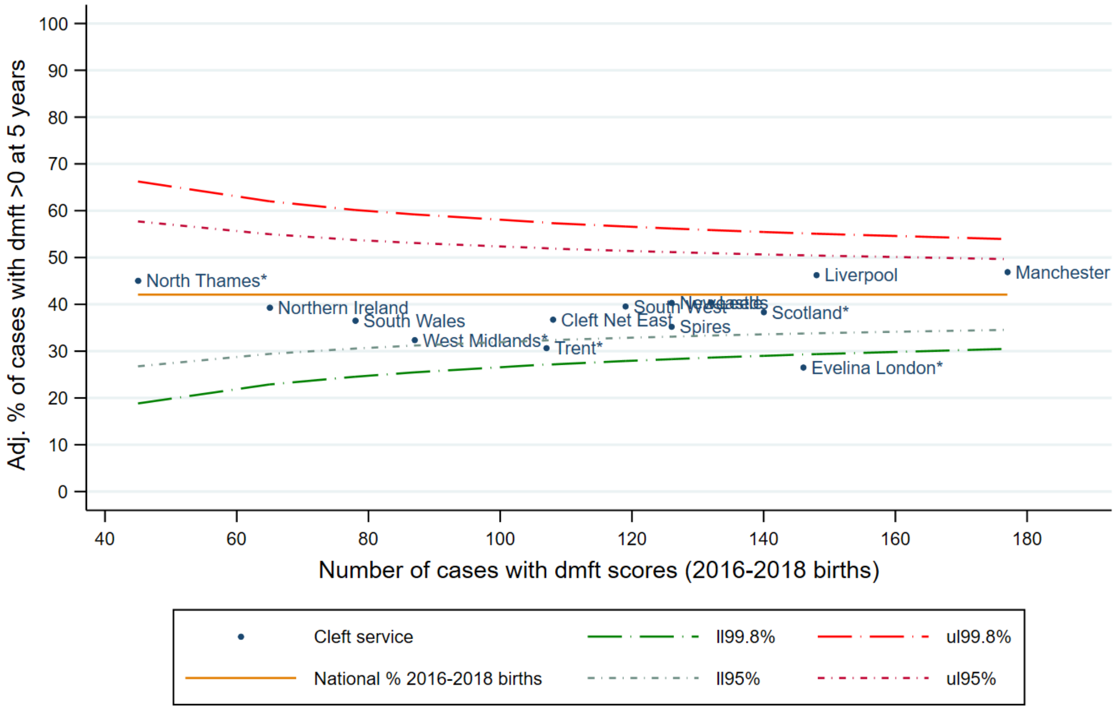


Note: Funnel plot centred on the revised national percentage (58.0%) of children (born 2016-2018) with dmft scores reported.

5.2.1. Dental decay

Outcome: dmft >0 scores	
Indicator	#13 – Dental decay at 5 years of age
Benchmarks	• The Oral Health Survey of 5-year-old children in 2022 reported that 29% of children in the general population of England had dental decay, with at least one (>0) dmft[24]. • 38% of eligible children born 2015-2017 were reported to have dmft >0 scores (CRANE, 2024).
Notes	Funnel plots are risk-adjusted for deprivation quintile, country, Robin Sequence status, cleft type, extent of palate involvement and sex, and they are centred on the revised national rate after excluding data from services identified as negative outliers for consent verification (Scotland and West Midlands) and dmft data completeness (North Thames, West Midlands, Trent and Evelina London).
Denominator	1,604 CRANE-consented children with a recorded total decayed, missing or filled teeth (dmft) score
What did we find?	• The mean number of dmft at 5 years was 2.2, with scores ranging from 0 to 24. • 39% of children with a cleft had at least one (>0) dmft (Cleft Service range: 23%[25]-57%, p=0.001). • The proportion of children with >0 dmft varied significantly according to cleft type (CL: 30%, CP: 39%, UCLP: 41%, BCLP: 49%, p<0.001), but not by birth year (p=0.935), sex (p=0.497) or ethnicity (p=0.117).
Outliers	Positive: 1. Evelina London (23%, adjusted 27%)[25] Negative: None

Figure 5.5. Funnel plot showing the adjusted[26] percentage of CRANE-consented 5-year-olds, born 2016 to 2018, with experience of dental decay (dmft >0), according to Cleft Service.



Note: Funnel plot centred on the revised adjusted national percentage (42.1%) of children (born 2016-2018) with >0 dmft.

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[24] National Dental Epidemiology Programme (NDEP) for England: Oral health survey of 5 year old children 2022 Data on children in the general population in Wales and Northern Ireland were not available at the time of producing this report.

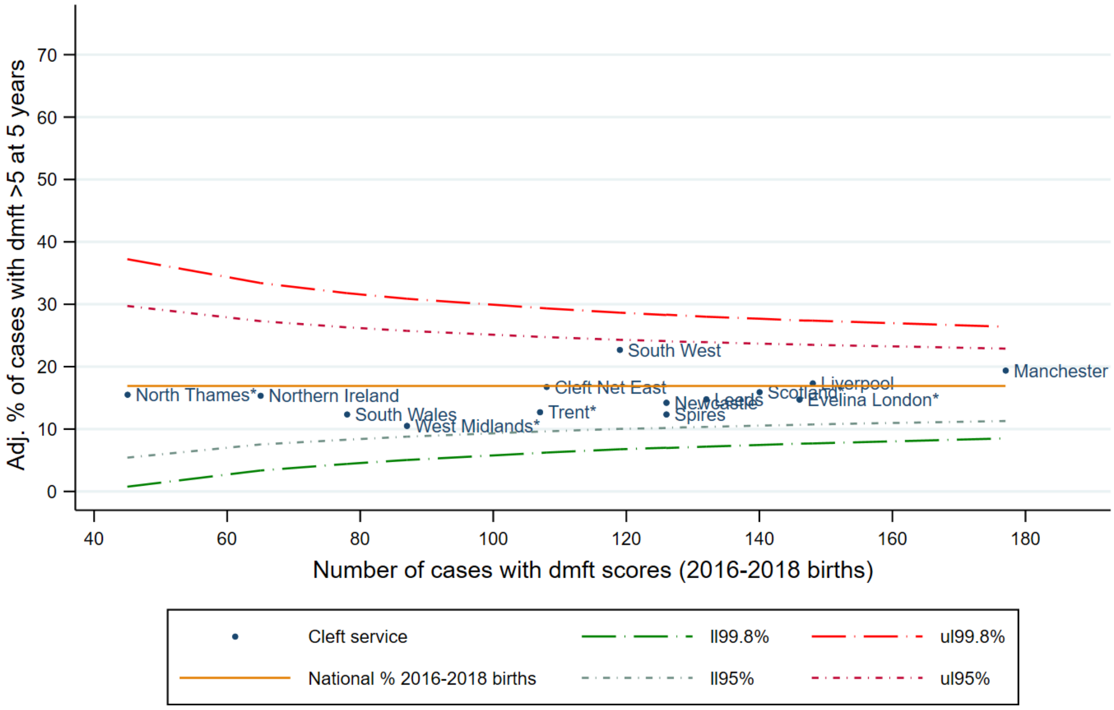
[25] Note that Evelina London (23%) was a negative outlier for data completeness so interpret this rate with caution. The lowest rate among services not identified as negative outliers for consent or data completeness was 29% (Spires).

[26] Adjusted for Index of Multiple Deprivation (IMD), country, Robin Sequence and year of birth

5.2.2. Extensive dental decay

Outcome: dmft >5 scores	
Indicator	#14 – Extensive dental decay at 5 years of age
Benchmarks	- The Child Dental Health Survey in 2013 reported that 13% of children in the general population of England, Wales and Northern Ireland had extensive dental decay (dmft >5) at 5 years of age[27][28]. - 15% of eligible children born 2015-2017 were reported to have dmft >5 scores (CRANE, 2024).
Notes	Funnel plots are risk-adjusted for deprivation quintile, country, Robin Sequence status, cleft type, extent of palate involvement and sex, and they are centred on the revised national rates after excluding data from services identified as negative outliers for consent verification (Scotland and West Midlands) and dmft data completeness (North Thames, West Midlands, Trent and Evelina London).
Denominator	1,604 CRANE-consented children with a recorded total decayed, missing or filled teeth (dmft) score
What did we find? 	- 16% of children with a cleft had extensive dental decay (dmft >5) (Cleft Service range: 9%-23%, p=0.132). - The proportion of children with dmft >5 varied significantly according to cleft type (CL: 11%, CP: 15%, UCLP: 16%, and BCLP: 23%, p=0.005), but not by birth year (p=0.457), sex (p=0.763) or ethnicity (p=0.333).
Outliers	Positive: None Negative: None

Figure 5.6. Funnel plot showing the adjusted percentage of CRANE-consented 5-year-olds, born 2016 to 2018, with extensive dental decay (dmft >5), according to Cleft Service.



Note: Funnel plot centred on the adjusted revised national percentage (16.9%) of children (born 2016-2018) with >5 dmft.

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[27] Child Dental Health Survey 2013, England, Wales and Northern Ireland - https://digital.nhs.uk/data-and-information/publications/statistical/children-s-dental-health-survey/child-dental-health-survey-2013-england-wales-and-northern-ireland

[28] Grewcock, R. E., Innes, N. P. T., Mossey, P. A., & Robertson, M. D. (2022). Caries in children with and without orofacial clefting: A systematic review and meta-analysis. *Oral Diseases*, 28, 1400–1411. **https://doi.org/10.1111/odi.14183**; Worth, V., Perry, R., Ireland, T. *et al.* Are people with an orofacial cleft at a higher risk of dental caries? A systematic review and meta-analysis. *Br Dent J* **223**, 37–47 (2017). https://doi.org/10.1038/sj.bdj.2017.581

5.2.3. Dental health measures of intervention

Treatment Index	
Indicator	#15 – No untreated disease, as measured by the dental treatment index at 5 years of age
Definition	Treatment Index reflects whether the mouth is dentally fit at that moment in time, i.e. if dental disease has occurred, the Treatment Index indicates the extent to which it has been dealt with and the degree to which the child has been rendered free from active decay. A dmft score of 0 or individual scores for all three ‘m’, ‘f’ and ‘dmft’ data items are required for the calculation of Treatment Index. When calculated, treatment indices range from 0 to 1 and are usually expressed as a percentage. Treatment indices with a value of 1 (100%) indicate that there is no untreated disease, which is the desired outcome. Average treatment indices of 100% can be indicators of having mechanisms in place to deal with any disease occurring and thereby provide the child with a caries free dentition.
Benchmarks	• The Oral Health Survey of 5-year-old children in 2022 reported that the average Treatment Index for children is 14% in the general population in England[29]. • The average Treatment Index for eligible children born 2015-2017 was 75% (CRANE, 2024).
Notes	• High mean treatment index scores indicate that children have high levels of treated dental disease. • Not subject to outlier policy but funnel plots provided to demonstrate variation in rates across services. • Funnel plots are centred on the revised national rates after excluding data from services identified as negative outliers for consent verification (Scotland and West Midlands) and dmft data completeness (North Thames, Evelina London, and West Midlands).
Denominator	1,604 CRANE-consented children with scores for the calculation of Treatment Index[30]
What did we find? 	• The average Treatment Index for these children was 75% (Cleft Service range: 63%-89%[31], $p<0.001$)[32]. • Treatment Index did not vary significantly according to cleft type ($p=0.150$), birth year ($p=0.849$), sex ($p=0.744$) or ethnicity ($p=0.066$).
Outliers	Positive: 1. Evelina London (89%), 2. Cleft Net East (86%) Negative: 1. Manchester* (63%) * Negative alert status for two consecutive reporting periods and therefore classed as outlier.

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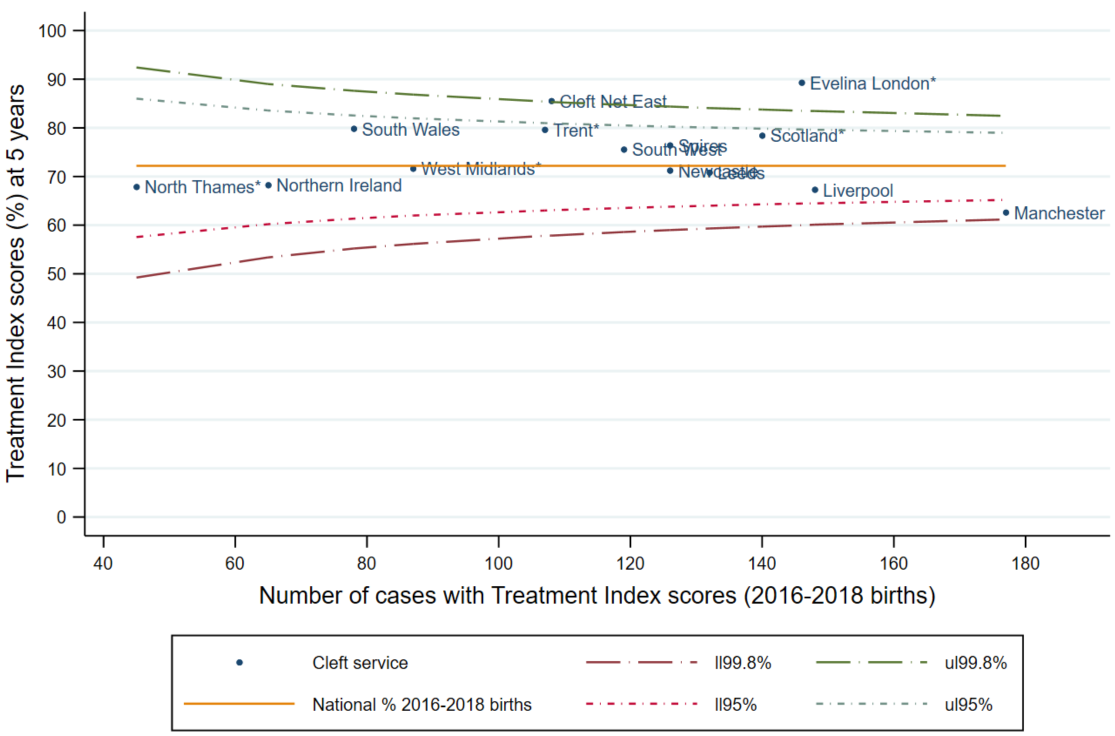
[29] National Dental Epidemiology Programme (NDEP) for England: Oral health survey of 5 year old children 2022

[30] Treatment Index calculated from missing teeth (m), filled teeth (f), and dmft scores; or a dmft score of 0 (equating to a treatment index = 1).

[31] Note that Evelina London (89%) was a negative outlier for data completeness so interpret this rate with caution. The highest rate among services not identified as negative outliers for consent or data completion was 86% (Cleft Net East).

[32] A Kruskall-Wallis test was used to compare the mean rank of Treatment Index scores between subgroups.

Figure 5.7. Funnel plot showing the average dental Treatment Index percentage for CRANE-consented 5-year-olds, born 2016 to 2018, according to Cleft Service.



Note: Funnel plot centred on the revised national Treatment Index percentage (72.2%) for children (born 2016-2018).

Outcome: Care Index	
Indicator	- #16 – No untreated disease, as measured by the dental care index at 5 years of age
Definition	- Care Index reflects the extent to which dental decay has been successfully treated by restorative techniques (e.g. fillings). A dmft score of 0 or scores for both ‘f’ and ‘dmft’ data items are required for the calculation of the Care Index. When calculated, care indices also range from 0 to 1 and are usually expressed as a percentage[33]. Care indices with a value close to 1 (100%) indicate that there are high levels of care provided by fillings (not extraction or no treatment), which is the desired outcome. In some cases, a tooth may be so malformed that it cannot be restored even if identified early and extraction may be the only option
Benchmarks	- The Oral Health Survey of 5-year-old children in 2022 reported that the average Care Index for children is 7% (100% is the desirable outcome) in the general population in England[34]. - The average Care Index for eligible children born 2012-2014 was 68% (CRANE, 2024).
Notes	- High mean care index scores indicate that children have received the appropriate care at the earliest possible stage. - Not subject to outlier policy but funnel plots provided to demonstrate variation in rates across services. - Funnel plots are centred on the revised national rates after excluding data from services identified as negative outliers for consent verification (Scotland and West Midlands) and dmft data completeness (North Thames, Evelina London, and West Midlands).
Denominator	1,604 CRANE-consented children with scores for the calculation of Care Index[35]

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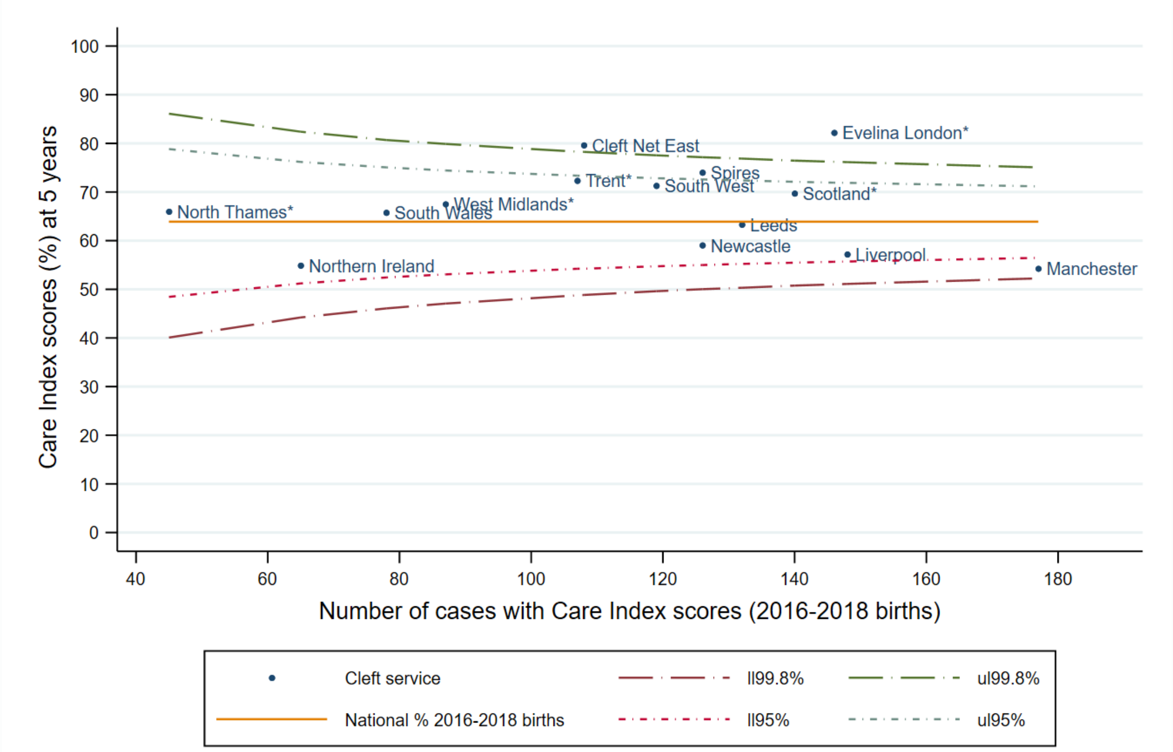
[33] If a dmft score for an individual is 0 then the Care Index is 1 (100%) as there is no dental disease.

[34] National Dental Epidemiology Programme (NDEP) for England: Oral health survey of 5-year-old children 2022

[35] Care Index calculated using: data on filled teeth (f) and dmft scores; or a dmft score of 0 (equating to a Care Index = 1).

What did we find?	- The average Care Index for these children was 67% (Cleft Service range: 54%-82%[36], p<0.001). - Care Index varied significantly according to cleft type (CL: 74%, CP: 66%, UCLP: 65%, and BCLP: 59%, p=0.002), but not by birth year (p=0.516), sex (p=0.669) or ethnicity (p=0.099).
Outliers	Positive: 1. Evelina London (82%)[36], 2. Cleft Net East (80%) Negative: 1. Manchester* (54%) * Negative alert status for two consecutive reporting periods and therefore classed as outlier.

Figure 5.8. Funnel plot showing the average dental Care Index percentage for CRANE-consented 5-year-olds, born 2016 to 2018, according to Cleft Service.



Note: Funnel plot centred on the revised national Care Index percentage (63.9%) for children (born 2016-2018).

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[36] Note that Evelina London (82%) was a negative outlier for data completeness so interpret this rate with caution. The highest rate among services not identified as negative outliers for consent or data completion was 80% (Cleft Net East).

5.3 Facial growth

Records of facial growth (study models or photographs) from 5-year-old children with a complete UCLP are assessed using the 5-year-old Index to examine dental arch relationships. The index has been used to evaluate the effects of primary surgery on the facial growth of children with UCLP before the use of any other interventions (e.g. orthodontics / alveolar bone grafting), which may influence growth[37]. Dental arch relationships at 5 years have been thought to predict treatment outcome in terms of facial growth on a population basis rather than at the individual child level[38]. The 5-year-old Index has, therefore, been used to compare treatment outcomes between Cleft Services. Patients scoring '1' and '2' on the index are considered to have good outcomes, while those scoring '4' and '5' are thought to have poor outcomes in terms of facial growth. Recently, data have been published showing that, whilst 'good' scores at 5 years of age have strong predictive value in terms of predicting the long-term (mid to late teenage years) value of dental arch relationships, 'fair' and 'poor' 5-year-old Index scores have limited predictive value[39]. As such, 'fair' and 'poor' scores should be interpreted with caution at 5 years of age.

Recommendations: Facial growth
• Cleft Services should aim to take records of all children born with a complete UCLP before they turn 6 years of age to support an external facial growth assessment using the 5-year-old index. These records may take the form of study models or clinical photographs with a recording of the overjet *(the horizontal gap between the front teeth)*. Study models can be made from dental impressions with a bite record or digital scans of the teeth and bite. Photography guidance should be sought from the IMI Guide to Good Practice for Cleft Lip and Palate (template 2a). • 100% of available records should be submitted for external scoring and validation to support benchmarking. • The research community should undertake to: ○ compare UK facial growth outcomes with those in other countries, and ○ evaluate the predictive value of the 5-year-old Index in UK populations.

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[37] Johnson N, Williams AC, Singer S, Southall P, Atack N and Sandy JR. Dentoalveolar relations in children born with a unilateral cleft lip and palate (UCLP) in Western Australia. The Cleft Palate-Craniofacial Journal, 2000. 37 (1): p. 12-16.

[38] Atack N, Hathorn IS, Semb G, Dowell T and Sandy JR. A new index for assessing surgical outcome in unilateral cleft lip and palate subjects aged five: reproducibility and validity. The Cleft Palate-Craniofacial Journal, 1997. 34 (3): p. 242-246.

[39] Pegelow M, Rizell S, Karsten A, Mark H, Lilja J, Chalien MN, et al. Reliability and Predictive Validity of Dental Arch Relationships Using the 5-Year-Olds' Index and the GOSLON Yardstick to Determine Facial Growth. The Cleft Palate-Craniofacial Journal 2020

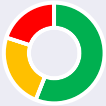
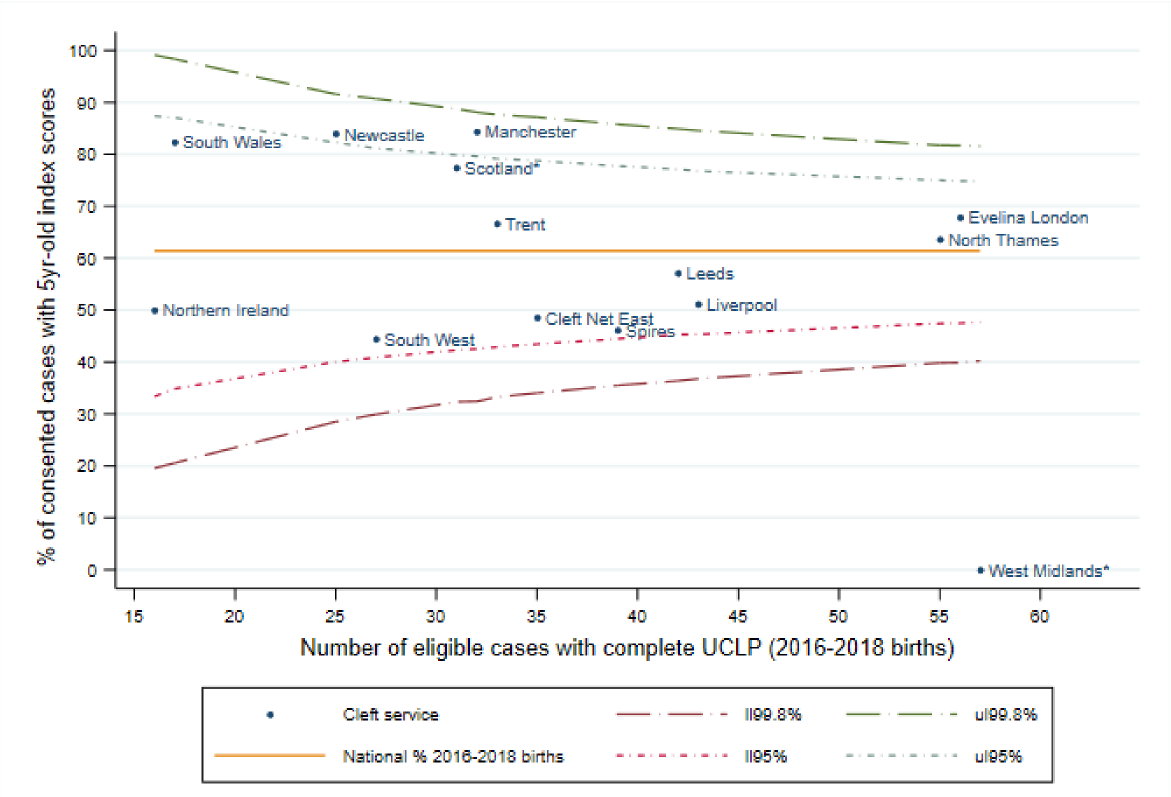
Data completeness: 5-year-old Index scores	
Raw data	‘Facial growth 2016-18’ in **the supplementary tables**.
Indicator	#17 – Facial growth at 5 years recorded for all eligible children.
Inclusions	Complete UCLP only
Denominator	508 CRANE-consented children with complete UCLP
What did we find? 	• 56% of eligible children had recorded 5-year-old Index scores (Cleft Service range: 0%-84%, p<0.001). This compares to 44% for the previous reporting period (births 2015-2017). • 233/282 (83%) scores were externally validated (Cleft Service range: 6%-100%)[40]. Most services had more than 85% of their scores externally validated; however, three had much lower rates (6%-55%). • Of the children with scores, 82% had clinical photos taken and 69% had study models made. • 24% had a reason the facial growth scores were not collected. • 20% were missing data and a reason for not collecting data. • The proportion of children with 5-year-old index scores did not vary significantly according to birth year (p=0.680), sex (p=0.701) or ethnicity (p=0.800).
Outliers	Positive: 1. Manchester* (84%), 2. Newcastle* (84%) Negative: 1. West Midlands (0%) * Positive alert status for two consecutive reporting periods and therefore classed as outlier.

Figure 5.9. Funnel plot showing the percentage of CRANE-consented 5-year-olds, born 2016 to 2018, with a complete UCLP who had facial growth data reported, according to Cleft Service.



Note: Funnel plot centred on the revised national percentage (61.4%) of children (born 2016-2018) with facial growth data reported.

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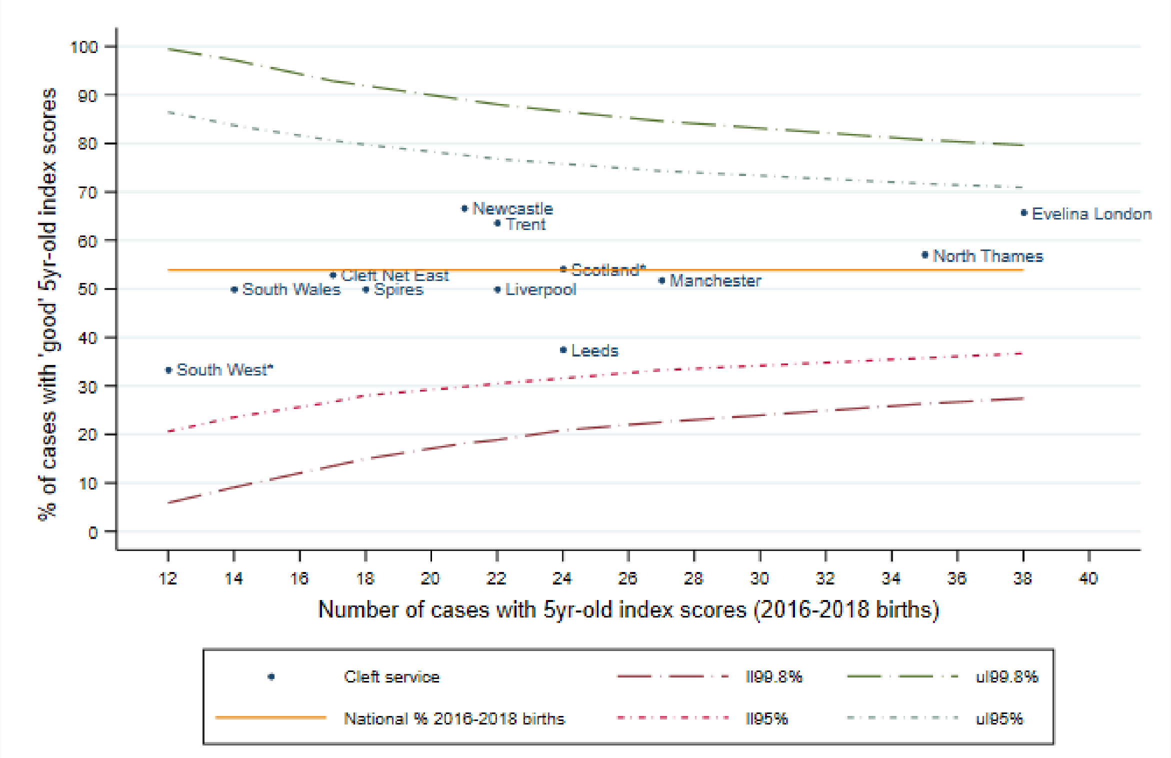
[40] Some units score the models of children treated in their unit (internal scores) before they are sent off to be scored externally (external scores) by a blinded process undertaken by calibrated examiners. For this report we have analysed externally validated scores where available; where these were unavailable, internal scores are included in the analyses.

Outcome: 5-year-old index scores	
Indicator	#18 – Children with Five-Year-Old Index scores reflecting 'good' dental arch relationships.
Benchmarks	• Cleft Care UK reported in 2015 that 53%, 28% and 19% of children with UCLP had 'good', 'fair' and 'poor' dental arch relationships, respectively[41]. • 52% of eligible children born 2015-2017 were reported to have 'good' scores (CRANE, 2024).
Notes	• Funnel plot is centred on the revised national rate after excluding data from services identified as negative outliers for consent verification (Scotland and West Midlands) and facial growth data completeness (West Midlands and South West). • West Midlands and Northern Ireland are not plotted due to insufficient data (n<10).
Denominator	282 CRANE-consented children with 5-year-old index scores
What did we find? 	• 54% of children had scores reflecting 'good' dental arch relationships at 5 years old (Cleft Service range: 33%-67%[42], p<0.001). This represents a 2% improvement on the previous reporting period (births 2015-2017) and is similar to the percentage reported in the Cleft Care UK study. • 31% of children had scores reflecting 'fair' dental arch relationships at 5 years old. • 16% of children had scores reflecting 'poor' dental arch relationships at 5 years old. • Among children with ethnicity reported (34%), those in the ethnic minority group were less likely to be assessed as having 'good' dental arch relationships compared with those from the white group (ethnic minority groups: 25%, White: 53%, p=0.044). Small numbers mean this result should be interpreted with caution. • The proportion of children with 'good' scores did not vary significantly according to sex (p=0.165) or birth year (p=0.958).
Outliers	None.

Figure 5.10. Funnel plot showing the percentage of CRANE-consented 5-year-olds, born 2016 to 2018, with a complete UCLP who had good facial growth scores, according to Cleft Service.



Note: Funnel plot centred on the revised national percentage (53.9%) of children (born 2016-2018) with 'good' facial growth outcomes.

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[41] Al-Ghatam, Jones, Ireland, Atack, Chawla et al. 2015 Structural outcomes in the Cleft Care UK study. Part 2: dento-facial outcomes. Orthodontics & Craniofacial Research 18(Suppl. 2): 14–24.

[42] among Cleft Services that submitted data for ≥10 cases.

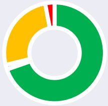
5.4. Speech

The Cleft Audit Protocol for Speech – Augmented (CAPS-A) tool has been used to assess speech among non-syndromic children with a cleft affecting the palate (CP, UCLP and BCLP). The 16 CAPS-A speech parameters include:

- Resonance (hypernasality and hyponasality) and nasal airflow (audible nasal emission and nasal turbulence). These are structurally-related speech characteristics reflecting aspects such as the ability of the palate to close off the nasal airway during speech.
- 12 individual cleft speech characteristics (CSCs) grouped into four categories of CSCs (anterior oral, posterior oral, non-oral and passive) are also assessed. These reflect articulation patterns which can affect the clarity and intelligibility of a child's speech.

Recommendations: Speech
• Cleft Services should ensure that all children with a cleft affecting the palate should have their speech at 5 years assessed and reported to CRANE. • Cleft Services should work together to explore reasons for variation in speech outcomes.

Statement written by Imogen Underwood, Chair of Lead Cleft Speech and Language Therapy (SLT) group, December 2025.
The COVID-19 pandemic has had a significant impact on each regional Cleft Service as they have had to respond to varying clinical demands on their service. This has led to wide variability in each of the services being able to collect, review and report speech data including missing data. This year's Annual Report contains speech data from the 2016 birth cohort impacted by the pandemic. This means data are not directly comparable across centres and the outlier data should be interpreted with caution. The Cleft SLT Lead group continue to drive for excellence across the UK and remain committed to the provision and submission of all available audit data.

Data completeness: CAPS-A scores	
Raw data	'Speech 2016-18' & '16-CAPS-A speech paramts' in **the supplementary tables**.
Indicator	#19 – Speech scores at 5 years recorded for all eligible children
Inclusions	Children with a cleft affecting the palate (CP, UCLP, BCLP)
Exclusions	Children with a diagnosed syndrome[43] entered onto the CRANE Database
Denominator	1,304 CRANE-consented children eligible for CAPS-A assessment
What did we find? 	• 70% of children had all 16 CAPS-A speech parameters reported (Cleft Service range: 52%-87%, p<0.001). This compares to 54% for the previous reporting period (births 2015-2017). Of those with speech data, 13% were assessed by an external CAPS-A trained listener (Cleft Service range: 0%-97%, p<0.001). • <2% had some but not all 16 CAPS-A speech parameters reported. • 26% had a reason the speech outcomes were not collected. • 3% were missing data and a reason for not collecting data. • The proportion of children with complete speech data varied significantly according to birth year (2016: 64%, 2017: 70%, 2018: 76%, p<0.001) and cleft type (CP: 67%, UCLP: 76%, BCLP: 67%, p<0.001), but not by sex (p=0.159) or ethnicity (p=0.650).
Outliers	Positive: 1. Trent (87%), 2 Newcastle* (85%) Negative: 1. West Midlands (52%), 2. South West (55%), 3. Evelina London (60%) *Positive alert status for two consecutive reporting periods and therefore classed as outlier.

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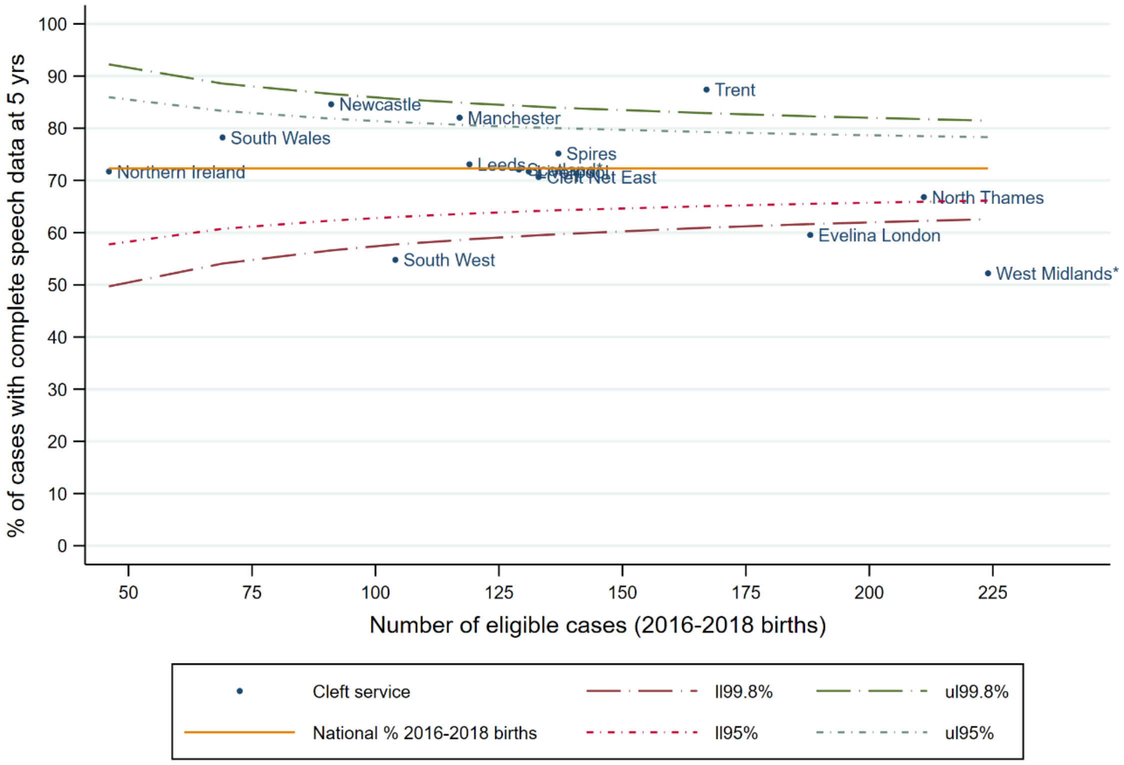
[43] Cases flagged as syndromic are excluded, with the exception of children with a recorded (named) congenital malformation of the circulatory system or congenital malformation of the nervous system (e.g. microcephaly, spina bifida).

Figure 5.11. Funnel plot showing the percentage of CRANE-consented 5-year-olds, born 2016 to 2018, with speech outcomes reported, according to Cleft Service.



Note: Funnel plot centred on the revised national percentage (72.3%) of children (born 2016-2018) with speech outcomes reported.

5.4.1 Speech Standard 1

Outcome: National Speech Standard 1	
Indicator	#20 – The achievement of speech with no evidence of a structurally related problem and no cleft speech characteristics requiring intervention: This standard is achieved when patients have green ratings across all 16 CAPS-A speech parameters.
Benchmarks	57% of children born 2015-2017 met speech outcome standard 1 (CRANE, 2024).
Denominator	1304 CRANE-consented children with all 16 CAPS-A scores.
What did we find? 	• 54% of children met speech outcome standard 1 (Cleft Service range: 33%[44]-71%, p<0.001). This is 3% lower than in the previous reporting period (births 2015-2017). • The percentage of children meeting standard 1 varied significantly according to cleft type (CP: 69%, UCLP: 44%, BCLP: 24%, p<0.001) and sex (female: 58%, male: 51%, p=0.008), but not by birth year (p=0.097) or ethnicity (p=0.667).
Outliers	Positive: 1. Trent (71%, adjusted 69%) Negative: 1. South West (33%, adjusted 32%), 2. North Thames* (41%, adjusted 42%), * Negative alert status for two consecutive reporting periods and therefore classed as outlier.

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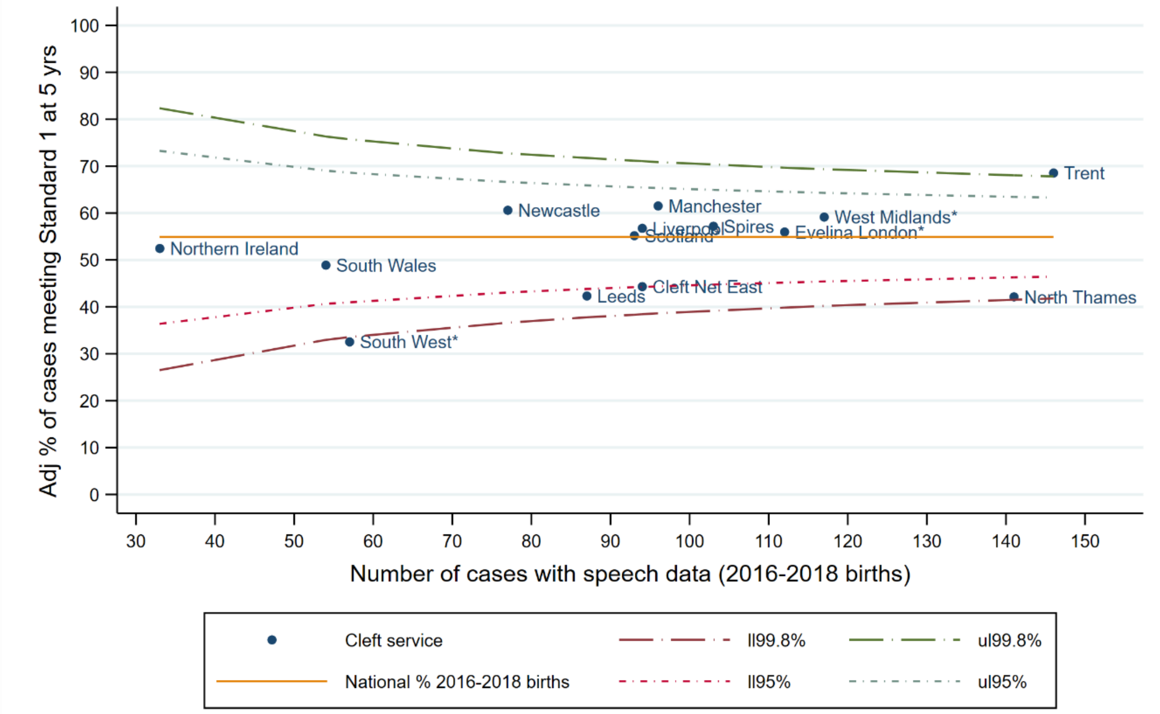
[44] Note that South West (33%) was a negative outlier for data completeness so interpret this rate with caution. The lowest rate among services not identified as negative outliers for consent or data completeness was 39% (Leeds).

Figure 5.12. Funnel plot showing the adjusted percentage of CRANE-consented 5-year-olds, born 2016 to 2018, meeting speech outcome standard 1, according to Cleft Service.



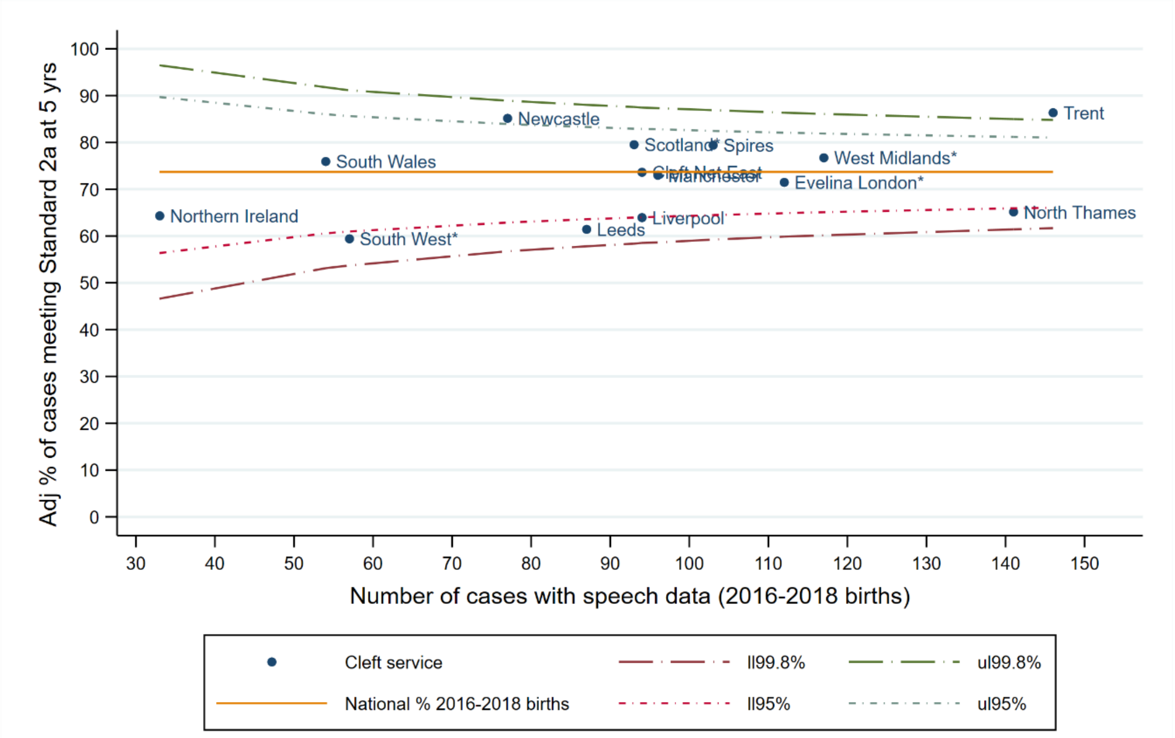
Note 1: Funnel plot centred on the revised national percentage (54.5%) of children (born 2016-2018) meeting speech outcome standard 1.
Note 2. Service-level rates adjusted for cleft type, extent of hard palate involvement, Robin Sequence status and sex.

5.4.2 Speech Standard 2

Outcome: National Speech Standard 2	
Indicator	#21 –The achievement of speech without evidence of a structurally-related speech difficulty. **Standard 2a** is achieved when 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. **Standard 2b** is met when patients have a history of velopharyngeal surgery or fistula repair and their speech now has no evidence of a structurally related problem **Standard 2c** is met when patients have a history of velopharyngeal surgery or fistula repair and their speech still has evidence of a structurally related problem **Standard 2d** is met when patients have not had velopharyngeal surgery or fistula repair and have current evidence of a structurally related problem
Benchmarks	73% of children born 2015-2017 met speech outcome standard 2a (CRANE, 2024).
Denominator	1,308 CRANE-consented children with all 16 CAPS-A scores.

What did we find?	• 74% of children met speech outcome **standard 2a** (Cleft Service range: 60%[45]-88%, p<0.001). This represents minimal change from the previous reporting period (2015-2017 births). • The percentage of children meeting **standard 2a** did not vary significantly according to cleft type (p=0.051), birth year (p=0.330), sex (p=0.416) or ethnicity (p=0.250). • 14% of children had secondary surgery for speech purposes (velopharyngeal surgery or fistula repair) before the age of 5 years (Cleft Service range: 4%-32%, p<0.001). This is a similar rate to those children born 2015-2017. • Among 188 children undergoing velopharyngeal surgery or fistula repair (14% of those with speech data): ○ 58% met **standard 2b** as they had no structural issues afterwards (Cleft Service range: 23% -82%, p=0.176) ○ 42% met **standard 2c** as they continued to have structural issues afterwards (Cleft Service range: 18%-77%, p=0.176) • 15% of 1,116 children who had not undergone) velopharyngeal surgery or fistula repair had evidence of a structurally-related problem and therefore met **standard 2d** (Cleft Service range: 7%-28%, p<0.001).
Outliers (S2a)	Positive: 1. Trent (88%, adjusted 87%), 2. Newcastle* (86%, adjusted 85%) Negative: 1. Leeds* (60%, adjusted 61%), 2. North Thames* (64%, adjusted 65%) * Alert status for two consecutive reporting periods and therefore classed as outlier.

Figure 5.13. Funnel plot showing the adjusted percentage of CRANE-consented 5-year-olds, born 2016 to 2018, meeting speech outcome standard 2a, according to Cleft Service.



Note 1: Funnel plot centred on the revised national percentage (73.7%) of children (born 2016-2018) meeting speech outcome standard 2a.
Note 2. Service-level rates adjusted for cleft type, extent of hard palate involvement, Robin Sequence status and sex.

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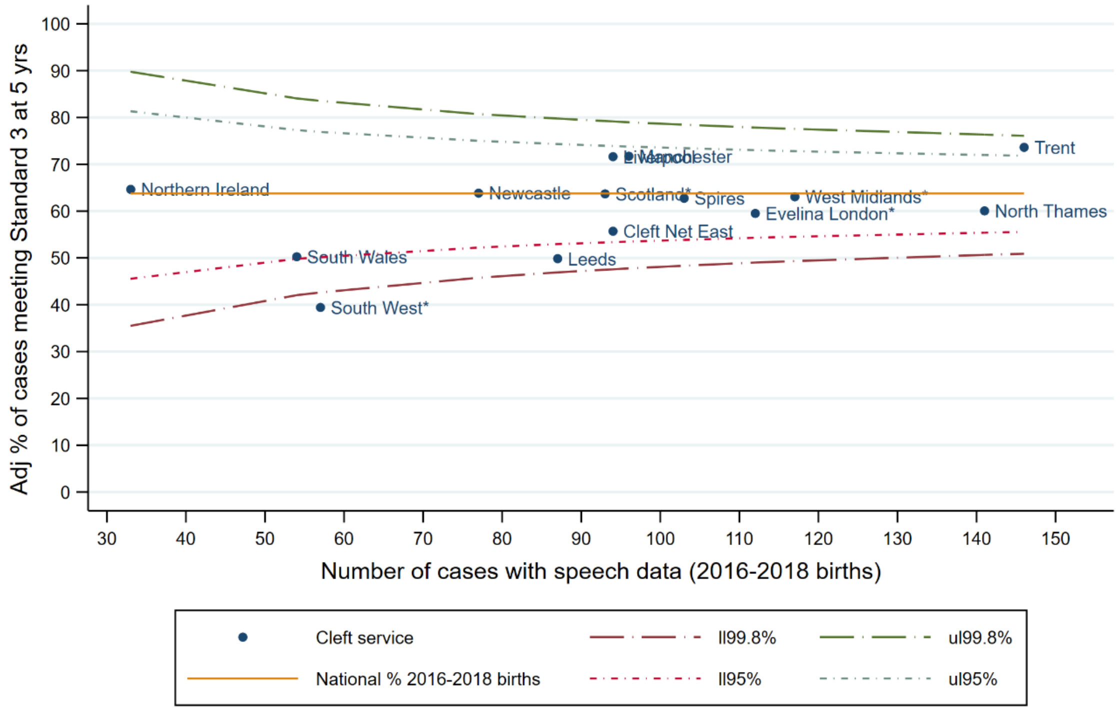
[45] Note that South West (60%) was a negative outlier for data completeness so interpret this rate with caution. The lowest rate among services not identified as negative outliers for consent or data completeness was 60% (Leeds).

5.4.3 Speech Standard 3

Outcome: National Speech Standard 3	
Indicator	#22 – The achievement of speech without evidence of significant cleft-related speech characteristics (on sentence repetition), which may require therapy and/or surgery: This standard is achieved when patients have green ratings across the following 10 CSCs: All three Anterior Oral CSCs, both Posterior Oral CSCs, all four Non Oral CSCs, and gliding of fricatives (a Passive CSC).
Benchmarks	65% of children born 2015-2017 met speech outcome standard 3 (CRANE, 2024).
Denominator	1,308 children with all 16 CAPS-A scores.
What did we find?	- 62% of children met speech outcome standard 3 (Cleft Service range: 40%[46]-76%, p<0.001). This is 3% lower than in the previous reporting period (2015-2017 births). - The percentage of children meeting standard 3 varied significantly according to cleft type (CP: 78%, UCLP: 52%, BCLP: 32%, p<0.001) and sex (female: 68%, male: 57%, p<0.001), but not according to birth year (p=0.304) or ethnicity (p=0.125).
Outliers	Positive: None Negative: 1. South West (40%, adjusted 40%)

Figure 5.14. Funnel plot showing the adjusted percentage of CRANE-consented 5-year-olds, born 2016 to 2018, meeting speech outcome standard 3, according to Cleft Service.



Note 1: Funnel plot centred on the revised national percentage (63.8%) of children (born 2016-2018) meeting speech outcome standard 3.
Note 2. Service-level rates adjusted for cleft type, extent of hard palate involvement, Robin Sequence status and sex.

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[46] Note that South West (40%) is a negative outlier for data completeness so interpret this rate with caution. The lowest rate among services not identified as negative outliers for consent or data completeness was 46% (Leeds).

5.5. Psychology

All children with a cleft should be seen by a psychologist before their 6th birthday. The **Tiers of Involvement Measure (TIM)** records the tier (level) of involvement by a psychologist from the Cleft Multi-Disciplinary Team (MDT). Tiers range from 0 to 6 (see box).

TIM Scores

0. Patient not seen by Psychologist
1. Psychological input not needed
2. Psychological input provided during the clinic
3. Psychological input provided following the clinic (tiers 3-6)

Recommendations: Tiers of Involvement

- TIM scores should be recorded for all CRANE-consented children.
- Cleft Clinical Psychology teams should aim to see all children and families before the age of 6 years and ensure that psychological support is provided if appropriate.
- Cleft Services should continue to collect Cleft Q data for children who are 10 years of age, born from 2015 onwards, and record this in CRANE once available on the Database.

Statement of ambition from the Psychology Clinical Excellence Network (CEN)

The Clinical Psychology CEN is comprised of a specialist group of Clinical Psychologists who work within Cleft Services in the UK. As a group, a decision was made in 2023 to retire the SDQ (see statement in 2023 CRANE Annual Report) as an outcome measure and to replace it with a measure that is cleft-specific, valid and reliable. As of 1 January 2025, the CEN agreed to utilise the Psychological and Social sub-sections of the CLEFT-Q for patients at aged 10. The CLEFT-Q is a rigorously developed patient-reported outcome measure (PROM) that can be used internationally to collect and compare evidence-based outcomes from patients aged 8 to 29 years with cleft lip and/or palate[47]. The CLEFT-Q has 12 independently functioning scales that measure three overarching domains: Appearance, Facial Function and Health-related Quality of Life (H-RQoL). The Psychological Functioning scale and the Social Functioning scale within the H-RQoL domain will be administered by a member of the Cleft Clinical Psychology team either face-to face or via video or phone with children who are 10 years of age. For more information about the introduction of the CLEFT-Q across UK Cleft Services, see the Appendix. The Clinical Psychology CEN have also agreed to collect the TIM score as a process measure at age 10 and submit this to CRANE.

The CLEFT-Q data and 10-year TIM data will be submitted to the CRANE Database in due course, once the Database has been updated for this purpose. It is anticipated that this change will be implemented ahead of the data extract deadline for the 2026 CRANE Annual Report.

Cleft Clinical Psychology teams will continue to collect the Tiers of Involvement Measure (TIM) data for 5-year-old patients for the time being, as a process measure.

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[47] CLEFT-Q | Q-Portfolio - MEASURING WHAT MATTERS TO PATIENTS: https://qportfolio.org/cleft-q/

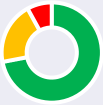
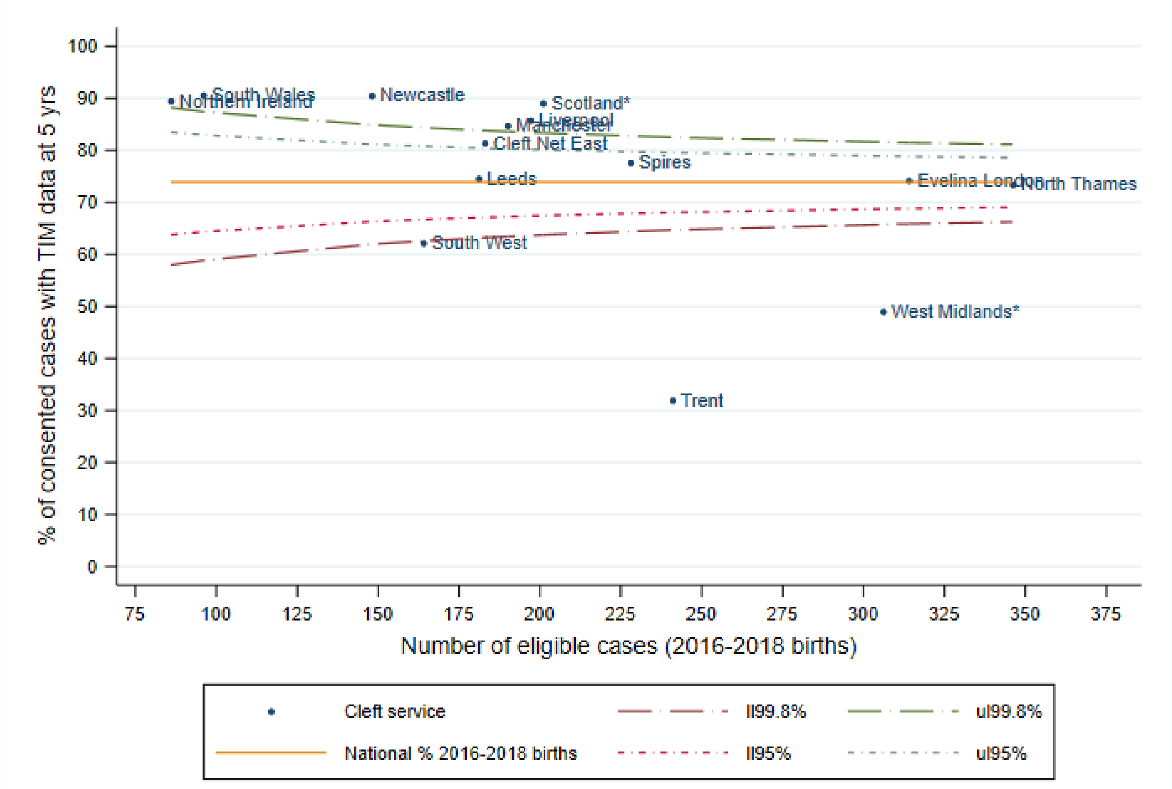
Data completeness: Tiers of Involvement score	
Raw data	‘Psychology 2016-18’ in **the supplementary tables**
Indicators	#23 – TIM scores recorded for all eligible children
Denominator	2,881 CRANE-consented children
What did we find? 	- 72% of eligible children had recorded TIM scores (Cleft Service range: 32%-91%, p<0.001). This compares to 57% for the previous reporting period (births 2015-2017). - 20% had a reason[48] TIM scores were not collected. - 8% were missing data and a reason for not collecting data. - The percentage of children with TIM scores varied significantly according to birth year (2016: 66%, 2017: 74%, 2018: 77%, p<0.001) and cleft type (CL: 69%, CP: 71%, UCLP: 77%, and BCLP: 77%, p=0.003), but not according to sex (p=0.981) or ethnicity (p=0.969).
Outliers	Positive: 1. South Wales (91%),2. Newcastle (91%), 3. Northern Ireland (90%), 4. Scotland (89%), 5. Liverpool (86%), 6. Manchester (85%) Negative: 1. Trent (32%), 2. West Midlands (49%), 3. South West (62%)

Figure 5.15. Funnel plot showing the percentage of CRANE-consented 5-year-olds, born 2016 to 2018, who had Tiers of Involvement Measure (TIM) scores reported, according to Cleft Service.



Note: Funnel plot centred on the revised national percentage (73.9%) of children (born 2016-2018) with TIM scores reported.

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[48] Additional reasons specific to psychology data collection: Screen only partially completed; Not completed due to language barriers; Parents declined to complete; Not appointed before 6 years.

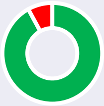
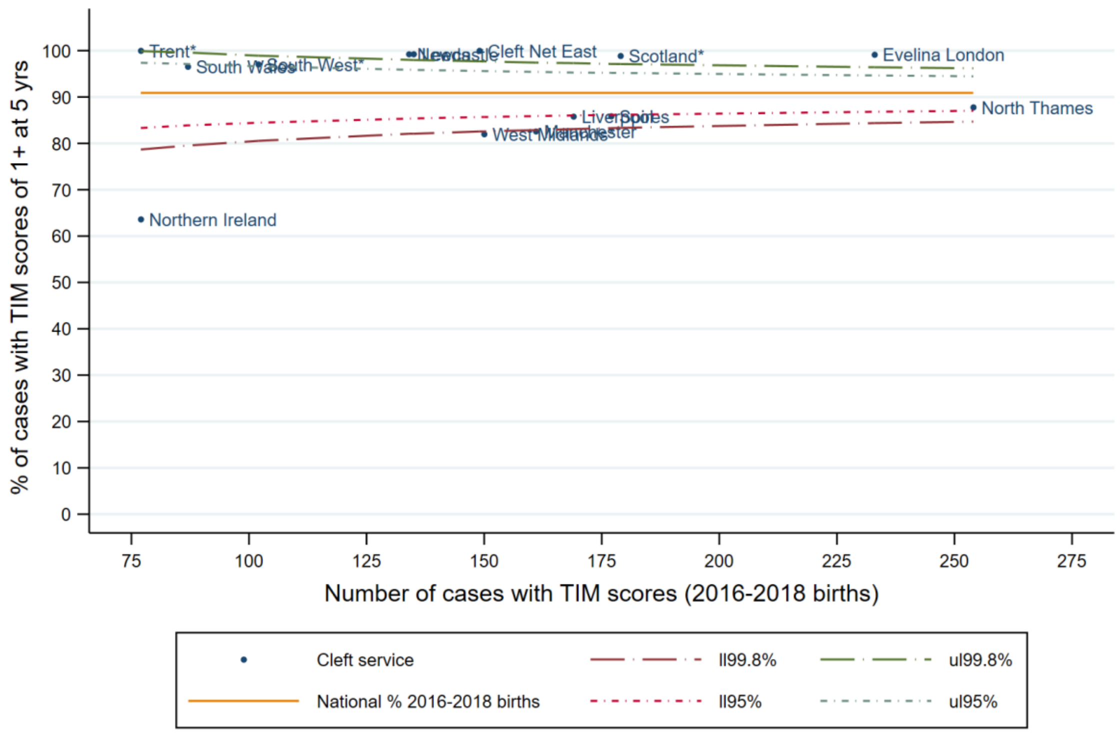
Outcome: TIM scores of 1+ (TIM tiers 1 to 6)	
Indicator	#24 – All eligible children seen by a psychologist before the age of 6 years.
Benchmarks	- 100% of children should be seen by a psychologist and have a TIM assessment - 92% of eligible children born 2015-2017 were reported to have TIM scores of 1+ (CRANE, 2024).
Notes	Funnel plot is centred on the revised national rates after excluding data from services identified as negative outliers for consent verification (Scotland and West Midlands) and TIM data completeness (Trent, West Midlands and the South West).
Denominator	2,084 CRANE-consented children with TIM scores
What did we find? 	- 92% of those with a TIM score were seen by a psychologist before the age of 6 years and a psychosocial screen was completed or psychological input arranged (TIM tiers 1 to 6, also referred to as TIM tier 1+) (Cleft Service range: 64%-100%, p<0.001). This remains unchanged since the previous reporting period (CRANE, 2024). ○ 24% were assessed as not needing psychological input (TIM score 1). ○ 59% received psychological input during the MDT clinic (TIM score 2). ○ 9% required further psychological action (TIM scores 3-6). - 8% were not seen by a psychologist (TIM score 0). - The percentage of children with TIM scores of 1+ did not vary significantly according to cleft type (p=0.309), birth year (p=0.920), sex (p=0.218) or ethnicity (p=0.277).
Outliers	Positive: 1. Cleft Net East (100%), 2. Trent[49] (100%), 3. Leeds (99%), 4. Newcastle (99%), 5. Evelina London (99%), 6. Scotland (99%) Negative: 1. Northern Ireland (64%), 2. West Midlands (82%), 3. Manchester[50] (83%)

Figure 5.16. Funnel plot showing the percentage of CRANE-consented 5-year-olds, born 2016 to 2018, with TIM scores of 1+, according to Cleft Service.



Note: Funnel plot centred on the revised national percentage (90.9%) of children (born 2016-2018) with TIM 1+ scores.

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[49] Negative outlier for data completeness so interpret this rate with caution.

[50] As part of the outlier process, Manchester investigated their TIM scores due to their position on the funnel plot. Their outlier response revealed that some of their cases had an inappropriate/incorrect TIM score submitted, which has since been corrected. Their revised percentage with TIM 1+ is 85.1%, which would change their status from negative outlier to negative alert.

6. Database development work

6.1 Organisational Audit

This year, CRANE conducted an Organisational Audit (OA) of Cleft Services across the UK at the request of NHS England (NHSE) Specialist Commissioning. It is the first comprehensive OA of Cleft Services to be performed since centralisation following the Clinical Standards Advisory Group (CSAG) report into the quality of UK cleft care in the late 1990s[51].

Methods

Design: A questionnaire was created to gather information on the organisation of Cleft Services at individual hospital trusts and Health Boards.

The OA was developed with input from the Cleft Development Group (CDG), including representatives from commissioning, services, and each cleft specialty Clinical Excellence Network (CEN), as well as other key stakeholders such as NHSE and the CRANE team.

Data collection: The OA focused on the 2024 calendar year and requested a single response from each Cleft Service in the UK via Clinical Leads, or other nominated persons, requiring a multi-professional effort within each service.

Analyses: Quantitative data were analysed and reported as frequencies or percentages, while qualitative data were assessed for themes.

Key findings

- 100% of Cleft Services responded.
- The majority (60%) of services are led by surgeons and most operate across multiple sites (average: five sites).
- There was considerable variation in commissioned services, staffing levels, and access to diagnostic and operative facilities.
- Many services deliver unfunded elements of care, raising concerns about sustainability.
- Workforce shortages and recruitment challenges are widespread, especially in psychology, orthodontics and paediatric dentistry.
- Equitability of access remains a challenge across geography and specialties, especially for paediatric dentistry and speech and language therapy.
- 80% of services reported having concerns about delayed detection or delayed referral of clefts, but only 40% said they were adequately funded to engage in training professionals outside of their service.
- The majority of services aimed to repair the lip by 3 or 4 months and the palate by 9 months; however, 33% reported delays to these timings during 2024.
- services are highly engaged with the CRANE Database and value its role in benchmarking and quality improvement.

Conclusion

The OA responses reflect the context of cleft care in the UK in 2024. The findings demonstrate that Cleft Services are complex and diverse, and they reinforce the need for a clear, well-resourced, and consistent model of cleft care delivery across the UK. The full OA report can be found here.

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[51] Clinical Standards Advisory Group. Clinical Standards Advisory Group: Report of a CSAG Committee on Cleft lip and/or palate. London: The Stationery Office; 1998

6.2 Conference contributions in 2025

1. Cleft case ascertainment and incidence in the CRANE Database compared with Hospital Episode Statistics data in England (15th International Congress on Cleft Lip/Palate and Related Craniofacial Anomalies (CLEFT2025), October 2025)
2. Cleft laterality and early educational outcomes at 7 years of age in England: Results from linked national datasets (15th International Congress on Cleft Lip/Palate and Related Craniofacial Anomalies (CLEFT2025), October 2025)
3. Sidedness in unilateral orofacial clefts: A systematic scoping review (15th International Congress on Cleft Lip/Palate and Related Craniofacial Anomalies (CLEFT2025), October 2025)
4. Children born with right sided unilateral cleft lip and palate are more likely to have permanent hearing loss at birth (15th International Congress on Cleft Lip/Palate and Related Craniofacial Anomalies (CLEFT2025), October 2025)
5. Early hearing status is a determinant of speech outcome at age 5 among children born with cleft palate +/- lip. Results from a study linking two national datasets in England (15th International Congress on Cleft Lip/Palate and Related Craniofacial Anomalies (CLEFT2025), October 2025)
6. Early hearing outcomes of children born with an orofacial cleft in England (15th International Congress on Cleft Lip/Palate and Related Craniofacial Anomalies (CLEFT2025), October 2025 and CFSGBI, April 2025)
7. Are children with an orofacial cleft more likely to be born in deprived areas than the general population? (CFSGBI, April 2025)

7. Conclusion

2025 has been a year of transition and progress for CRANE. We have said farewell to valued colleagues whose commitment and expertise have shaped the project over many years. We thank them sincerely for their contribution and wish them every success in the future. We also welcome new members to the team, whose energy and fresh perspectives will support CRANE's continued growth and impact.

This year has also marked a major step forward in the quality and sophistication of CRANE reporting. For the first time, both speech and dental outcomes are presented using risk-adjusted analyses. Risk adjustment is central to national audit and outlier management, as set out by the Health Quality Improvement Partnership (HQIP). Incorporating risk adjustment enables us to be more confident that variation in outcomes between Cleft Services reflects true differences in performance, rather than differences in case mix. This is a significant milestone. It strengthens our ability to highlight excellence, facilitate shared learning, and support the spread of effective practice across the United Kingdom, while also allowing clearer identification of areas requiring improvement. CRANE remains committed to working collaboratively with clinical teams, patients, and communities to drive meaningful improvement.

The full engagement of all services with the new outlier process reflects a positive culture of transparency and improvement, and the completion of the UK-wide Organisational Audit of Cleft Services provides a clear foundation for future planning. To build on this progress, investment in workforce capacity, consistent data capture and support for early detection pathways will be essential.

As we enter this new phase of embedding risk-adjusted outcome reporting as part of our established outlier framework, CRANE will continue to evolve processes and ensure that outputs provide maximum value to clinicians, commissioners, families, and the public. We look forward to building on the foundations laid to date, and to seeing the collective efforts of the cleft community translate into better care and improved outcomes for children and young people.

Glossary and abbreviations

Alveolus / alveolar	The part of the jaw (gum) that supports the teeth and contains the tooth sockets.
BCLP	Bilateral cleft lip and palate
CAPS-A	Cleft Audit Protocol for Speech—Augmented
Caries (dental)	Dental caries are also known as tooth decay / dental decay or a cavity.
CEN	Clinical Excellence Network – previously referred to as Special Interest Group (SIG)
CI	Confidence interval
CL	Cleft lip only
Cleft	A failure of tissues to join during development.
Cleft Development Group (CDG)	NHS national group representing all stakeholders in cleft care that is responsible for the CRANE Database as well as oversight and guidance on all aspects of the delivery of reorganised cleft care.
Cleft Services / regions	These terms are used interchangeably throughout this report and refer to the hospital / multidisciplinary group that provides cleft surgery and care for children with a cleft; as well as submits data to the CRANE Database, sometimes as part of a wider cleft centre or network. See **the supplementary tables** for further information on Regional Cleft Services.
Cleft surgeon	A surgeon undertaking cleft repair surgery in a region / Cleft Service.
Clinical Standards Advisory Group (CSAG)	A group established in 1991 to act as an independent source of expert advice on standards of clinical care for, and access to and availability of services to, NHS patients.
Confidentiality Advisory Group (CAG)	An independent statutory body established to promote, improve and monitor information governance in health and adult social care. http://www.hra.nhs.uk/research-community/applying-for-approvals/confidentiality-advisory-group-cag/
CP	Cleft palate only
Craniofacial anomalies	A diverse group of deformities in the growth of the head and/or face.
Craniofacial Society of Great Britain and Ireland (CFSGBI)	An inter-specialty group set up to study cleft lip and palate and other craniofacial anomalies. https://craniofacialsociety.co.uk/
CSCs	Cleft Speech Characteristics
Denominator (see also numerator)	In mathematical terms, the bottom number in a fraction. Considering that a fraction represents a part of a whole, the denominator represents the total number of parts created from the whole, for example 100 in 70/100. In the context of this report, we refer to the number of children in the cohort we are discussing that could meet certain criteria. For example, children with a Cleft Palate (CP) only.
dmft	Decayed, missing and filled teeth at 5 years of age
Funnel plot	A graph that identifies Cleft Services which are outliers, where the local situation might require closer inspection – either because an area is doing well or because there is some indication that it is performing poorly. In this report: • Each point on the funnel plot represents a Cleft Service. • Each funnel plot is for one outcome, with its values shown on the vertical/Y axis. • The size of the Cleft Services' cohort is shown on the horizontal or X axis. • The benchmark value or overall national percentage is shown as a horizontal line through the centre of the graph. The graph shows two funnels that lie on either side of the benchmark and are called the control limits – similar to confidence intervals.

	• The inner lines show 2 standard deviations or 95% control limits. The outer lines represent 3 standard deviations or 99.8% control limits. • The funnel shape is formed because the control limits get narrower as the population size increases. The outer funnel is used to decide if an area is significantly different to the benchmark with 99.8% confidence. If a point lies within the funnel, then we conclude that it is not significantly different to the benchmark. If it falls outside the funnel then we can say the value is significantly ‘better’ or significantly ‘worse’ than the benchmark, depending on the direction of the indicator/outcome. Funnel Plot Source: David Spiegelhalter, Medical Research Council Biostatistics Unit - http://www.erpho.org.uk/Download/Public/6990/1/INPHO%204%20Quantifying%20performance.pdf
General population	In epidemiological terms, all individuals without reference to any specific characteristic. In the context of this report, and to aid comparison, we sometimes refer to the latest national figures for children in the general population, which may also include children with a cleft or other health conditions. E.g. gestational age and birthweight in the general population of England & Wales, according to the Office for National Statistics (ONS) (as in the Registrations section of this report). In some instances, the latest national figures are based on a random sample of children in the general population, which, again, may include children with a cleft or other health conditions.
LAHSAL	A code used to classify cleft type. Each letter (LAHSAL) relates to one of the six parts of the mouth that can be affected by a cleft.
MD	Multiple Deprivation
MDT	Multi-disciplinary team.
National Hearing Screening Programme (NHSP)	The Newborn Hearing Screening Programme (NHSP)[52], commissioned by the National Health Services for England (NHSE), is responsible for hearing loss detection among all English newborns. The NHSP database contains information on the screening assessment, usually performed within the first few weeks after birth, as well as referral status for audiological assessment and type of hearing loss detected, if present.
Numerator (see also denominator)	In mathematical terms, the top number in a fraction. Considering that a fraction represents a part of a whole, the numerator represents how many parts of that whole are being considered, for example 70 in 70/100. In the context of this report, we refer to the number of children meeting certain criteria. For example, receiving a certain type of care or meeting a standard.
RS	Robin Sequence is a congenital birth condition characterised by micrognathia, glossoptosis and failure to thrive with or without a cleft affecting the palate.
SD	Standard deviation
SDQ	Strengths and Difficulties Questionnaire
SLT	Speech and language therapy
Submucous cleft palate (SMCP)	The term submucous refers to the fact that the cleft is covered over by the lining (mucous membrane) of the roof of the mouth. This covering of mucosa makes the cleft difficult to see when looking in the mouth.
TIM	Tiers of Involvement Measure
UCLP	Unilateral cleft lip and palate
WHO	World Health Organization

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[52] Overview of NHSP https://www.nhs.uk/conditions/baby/newborn-screening/hearing-test/ [Last accessed: 24/02/2023]

Appendix. Introduction of the CLEFT-Q to CRANE

The rationale for changing what the Psychology Clinical Excellence Network (CEN) submits to CRANE was shared in the 2023 report so will not be repeated here. A CRANE-CEN sub-group was set up in December 2023 comprising a senior Clinical Psychologist from each Cleft Centre across the UK. From January 2024 the sub-group has met four times to decide what we collect and how we plan to collect it.

We have agreed to use the CLEFT-Q as our outcome measure. The CLEFT-Q was developed by Drs Anne Klassen and Karen Wong. The copyright is owned by McMaster University (Hamilton, Canada) and the Hospital for Sick Children (Toronto, Canada). The measure can be used for free for non-profit purposes, but users must sign a Licensing Agreement. For further information about this, please email the McMaster Liaison Office via milo@mcmaster.ca. This is the only validated and published cleft-specific measure of its kind to date.

To develop the measure, the authors used a concept driven approach: 138 concept elicitation interviews for children and young people with a cleft diagnosis aged eight to 29 years from six different countries were carried out. Content validity was established by conducting 69 cognitive interviews with feedback and advice obtained from 44 international experts. It was then field tested in an international sample of 2,434 patients from 30 hospitals in 12 countries. The authors of the CLEFT-Q state that “It represents a new generation of PROMS developed using a modern psychometric approach called the Rasch Measurement Theory”. The team followed internationally recommended guidelines to create the CLEFT-Q. A detailed description of the protocol has been published: https://bmjopen.bmj.com/content/10/3/e032332.

The CLEFT-Q has 12 independently functioning scales that measure three overarching domains, and one checklist. Given the variety of scales, this provides clinicians with the flexibility to choose particular subsets of scales to measure their outcome of interest. The authors of the measure advise that the CLEFT-Q is included in ICHOM Standard Sets for craniofacial conditions to enable hospitals around the world to compare outcomes. This sets the measure up as an ideal tool to use across the UK as a way of comparing our outcomes nationally. Our data could be compared internationally in the future. Please see the CLEFT-Q website for further details on its development. The CLEFT-Q Users Guide can be found here: CLEFT-Q-USERS-GUIDE.pdf (qportfolio.org)

Each of the three domains within the CLEFT-Q is composed of one or more independently functioning scales. The three domains are: Appearance, Facial Function and Health-related Quality of Life (H-RQoL). Within H-RQoL, there are four scales: psychological, social and school functioning and speech-related distress. The CEN has agreed that we will utilise the Psychological and Social Functioning sub-scales to submit to CRANE, as there is a degree of over-lap with the school functioning sub-scale and we felt that speech-related distress was more specific to our Speech and Language Therapy colleagues.

Having reviewed our cleft cohort, it was also agreed that we would collect data for patients aged 10. We felt that this was a clinically beneficial time, given children would be transitioning to secondary school aged 11 and that attendance at clinic appointments aged 10 is optimal, as patients are also invited to meet with other members of the MDT at that age. This means we are likely to obtain data from a representative sample of our patients. We also felt that seeing patients aged 10 reflected a more proactive intervention from Psychology, as issues can be identified as children also transition into adolescence, which we recognise can result in an increase in psychological distress. We discussed meeting with 15- or 20-year-olds but identified that attendance is less optimal at these ages due to school exams, further education or work commitments, which could impact outlier status for all and compromise the validity of our findings. We all agreed that we want to ensure that we collect data that is meaningful and informative for Clinical

Psychology, our MDT colleagues and for our Patients. There was consensus that the use of these two CLEFT-Q sub-scales provides an optimal opportunity to do so.

We recognise that different Centres work differently and that the agreed changes would be more difficult to introduce in some centres than others. With that in mind, having confirmed the measure that we want to use, each Centre was tasked with conducting their own feasibility study between April 2024 and September 2024. Each Centre was asked to register to access the measure in order to sign their own Licensing Agreement and to consider their staffing, room availability and administrative support. To obtain a licensing agreement, please use the following link: https://research.mcmaster.ca/industry-investors/technologies-available-for-licensing/request-for-license/ Our CRANE representatives were made aware that they will need a licensing agreement in order to analyse the national data. Dr Jo Shearer contacted the CLEFT-Q team to request liaison with CRANE (see email dated 03.10.24).

The CLEFT-Q comes in multiple languages. The translation list can be found here: http://www.qportfolio.org/. It is the responsibility of each Cleft Centre to liaise with CLEFT-Q for access to any languages that they may require. Our Welsh colleagues are in liaison already about access to Welsh versions as this is not currently on the list. It is the responsibility of each Cleft Centre to liaise with CLEFT-Q about using electronic copies of the measure. Please review the User's Guide. The CLEFT-Q Computerized Adaptive Test (CAT) is available. It uses algorithms to select the most relevant items from each scale, based on the responses provided up to that point. There may be a small administration charge for using the CAT. The CEN do not feel this is required for the purposes of CRANE, as we will be using only two of the 12 sub-scales, which we believe will not be burdensome to our Patients.

We have agreed that a member of the Clinical Psychology Service will meet with individuals either face-to-face or via video to complete the CLEFT-Q. This can include pre-qualified staff, providing they receive adequate training beforehand and have access to supervision from a qualified Clinical Psychologist. In order to ensure equity of access, telephone consultations can be carried out if a family cannot attend in person and does not have access to technology to attend a video consultation.

We agreed that each Centre would contact Dr Jo Shearer (CEN CRANE Rep) and Dr Kat Berlouis (Locum CEN Chair) with any pressing concerns by September 2024. The time frame involved feedback to CRANE by October 2024 so that the database could be built, with a view to submitting data from January 2025. This meant data collection began from January 2025 for those born in 2015. We recognise that we will need to collect data for three years before the data reaches maturity and that CRANE cannot analyse any data for the first 12 months.

The CEN has also been considering whether to collect 10-year Tiers of Involvement (TIM) scores with a view to retiring the 5-year TIM once the data reaches maturity. The CEN has now confirmed this plan is going ahead, and we have agreed to also begin collecting 10-year TIM data from January 2025 and hold this data locally, with the hope that the CRANE database can be updated to accommodate this as an additional data set that can be analysed, in future. The CEN have agreed that we will continue to collect 5-year TIM scores for now.

Whilst we have made every effort to future proof our decision, we recognise that we cannot predict changes in the longer term. We are also aware that with time, new cleft-specific measures may become available that may be deemed more beneficial to our patients in terms of understanding their psychological outcomes. For now, we feel that the two sub-scales reflect many of the themes we come across within our clinical practise, the results of which will support us in understanding and supporting our patients.

Dr Jo Shearer
Principal Clinical Psychologist
Lead Clinician for North Thames Cleft Lip/Palate Service, Maxillofacial & Dental Services
CRANE Representative for the Psychology CEN