CLEFT REGISTRY & AUDIT NETWORK

Promoting excellence in cleft care

CRANE 2025 Annual Report:
Summary of findings for the cleft community

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

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CLAPA Cleft Lip & Palate Association

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Summary of the CRANE 2025 Annual Report findings

1. What is a cleft lip and/or palate?

An orofacial cleft is a gap in the upper lip (cleft lip), the roof of the mouth (cleft palate), or sometimes both (cleft lip and palate). It is a common condition, affecting 1 in 660 births, and can affect feeding, growth, speech, hearing, dental and psychosocial health.

There are many types of cleft: cleft palate (CP), cleft lip (CL), one-sided clefts known as unilateral cleft lip and palate (UCLP), clefts on both sides of the lip and palate known as bilateral cleft lip and palate (BCLP), submucous cleft palate (SMCP) hidden under the surface of the palate, and SMCP with a CL. All can be complete or incomplete.

2. What is the CRANE Database?

The Cleft Registry and Audit NEtwork (CRANE) Database is a national clinical registry that collects information about all children born with cleft lip and/or cleft palate in the UK. It was established in 2000, by the Department of Health[*].

CRANE now has records for over 26,000 children born with a cleft since 1 January 2000. 901 children were born with a cleft in 2024.

CRANE is also a national clinical audit. An audit in healthcare is a process aimed to improve patient care and outcomes by reviewing clinical practices against standards. CRANE is committed to helping professionals provide evidence-based cleft care through the information we make available in our reports.

3. Why is information collected?

Improve care and treatment by highlighting and sharing learnings of best practice.

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

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

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

4. How is information used?

- ☑ Data is analysed and summarised in reports for both cleft teams and cleft service users
- ☑ Names or details that could identify a child are never shared publicly
- ☑ Quality improvement activities are run to highlight and share learnings of best practice

We do not use any information in our reports that could identify children or their families.

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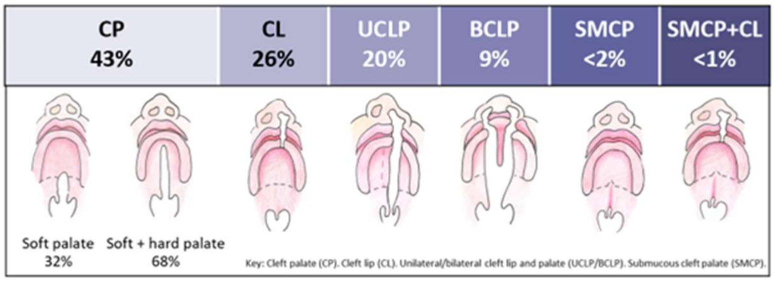
[*] CRANE is overseen and guided by the Cleft Development Group – *see the Glossary for more information on this*.

5. What do we know about CRANE-registered children who were born between 2022 and 2024?

Cleft type

Cleft palate only is the most common type of cleft, affecting just under half of all clefts. Around 30% have cleft lip and palate. Of these, two thirds are unilateral (one side) and one third are bilateral (both sides). One quarter of clefts affect only the lip.



23% of children with cleft palate alone were reported to have **Pierre Robin Sequence (PRS)**, a condition characterised by micrognathia (smaller than usual jaw), glossoptosis (when the tongue sits far back in the mouth, towards the throat) and breathing difficulty. The rate of children with this condition varies between services.

Recommendation:

Services should work to agree on clinical thresholds for classifying PRS to ensure consistency.

Early diagnosis

78% of babies with a **cleft affecting the lip** were **diagnosed during pregnancy**.
74% of babies born with **cleft palate only** (except SMCP) were **diagnosed before or at birth**.
This increased to **84%** when including diagnoses within the first **72 hours after birth**.

Recommendations:

Services should work to diagnose clefts as early as possible, ideally before or soon after birth, and share learning where diagnosis is delayed and where early diagnoses are frequently achieved.

Early diagnosis (before or soon after birth) should be supported by better training for midwives, neonatal teams, GPs, health visitors and tongue-tie specialists.

Birth

13% of babies born with a cleft were **born prematurely** (before 37 weeks of pregnancy), compared to 8% in general population.
14% of all babies born had a **low birthweight** (less than 2,500g). **6%** of babies born at term had a low birthweight. These rates are **twice as high** as those reported in the general population.

Recommendations:

Maternity services should be made aware that an antenatal cleft diagnosis increases the chance of premature birth and low birthweight.

The research community should investigate the higher percentage of premature births and babies with low birthweight among babies diagnosed with a cleft compared to rates in babies overall.

Early support

88% of families with an **antenatal diagnosis** were **contacted by the cleft team within 24 hours** of referral.
82% of all babies with a cleft were **referred to their local cleft team within 24 hours of birth**, and
97% of all families were **contacted by the cleft team within 24 hours of postnatal referral**.

Recommendation:

Cleft Services that have high levels of referrals and contacts within 24 hours should share their best practice recommendations with Cleft Services not meeting these standards.

CRANE Consent

97% of families approached gave **consent for CRANE** to collect information about their child's cleft care and progress measures throughout childhood.

Recommendation:

Cleft teams should share CRANE information with families shortly after referral and obtain their decision on consent.

6. What do we know about 5-year-old children, born between 2016 and 2018?

This section summarises key progress measures for 5-year-old children born with a cleft between January 2016 and December 2018. This is only recorded for children with CRANE consent. Age 5 is the standard time point when children with a cleft in the UK attend a cleft clinic so that progress can be assessed.

Growth

84% had a **healthy weight** for their height (BMI). **4%** were **underweight**, **8%** were **overweight** and **5%** were **obese**. In the general population of 5-year-olds, it is estimated that 77% have a healthy BMI, 1% are underweight, 12% are overweight, and 10% are obese.

Recommendation:

Research should explore reasons why the BMI distribution differs between the cleft and general population of 5-year-olds.

Dental health

61% had **good dental health**. **39%** had **decayed, missing or filled teeth**. This is higher than the rate seen in the general population (29%).

Recommendation:

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.

Facial growth

52% of children with a complete unilateral cleft lip and palate (UCLP) had what is known as 'good' facial growth when examined by orthodontists (using an assessment called the Five Year Old Index).

The index/measurement assesses dental arch relationships (how the upper and lower teeth fit together) at 5 years and can predict treatment outcome in terms of facial growth on a population basis, rather than at the individual child level. 'Good' facial growth scores have been found to be better predicters of longer term (mid to late teenage years) dental arch relationships than 'poor' and 'fair' scores.

Recommendation:

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).

Speech

74% had **speech without structurally-related** issues.

54% had **speech similar to their peers without a cleft**.

62% had **speech without any cleft-related characteristics** that require therapy or surgery.

Speech results differ depending on the type of cleft. Typically, children with a cleft affecting the palate alone do better than those with a cleft affecting both the palate and lip. **Results also vary by cleft team**.

Recommendation:

Cleft Services should work together to explore reasons for variation in speech outcomes, and services with the best results should share best practice recommendations.

Psychological screening

92% had **a psychosocial screen** (a check-in about wellbeing) before the age of 6 years. Of these, **24%** was assessed to **not need any support**, **59% received input** during a cleft clinic, and **9% required further input**. CRANE also collects data at later ages (10 years), which will be reported in future audits.

Recommendation:

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.

7. Organisational Audit

CRANE carried out a review of Cleft Services in early 2025 as requested by NHS England.

- All Cleft Services took part and responded to the survey reflecting on care provided in 2024.
- The review found large differences between services in what is provided, staff numbers, and access to tests and surgery.
- Many services do not have enough staff, especially in psychology, orthodontics and children's dentistry.
- Getting equal access to care is still difficult in some areas, particularly for dentistry and speech therapy.
- 8 out of 10 services are worried that clefts are sometimes found or referred late. But only 4 out of 10 have enough funding to train other professionals to help diagnose clefts earlier.
- Most services aim to repair the lip by 3-4 months old and the palate by 9 months. However, about one third had delays to these timings in 2024.
- Services are very involved with the CRANE Database and find it useful for checking quality and making improvements.

The full CRANE Organisational Audit report is available here.

8. Do Cleft Services in the UK provide the same treatment?

The CRANE report highlights any Cleft Services whose results are different from the national average, known as "outliers". This does not necessarily mean poor care. Services are given the chance to check and explain their data before anything is published. The purpose of identifying outliers is to support improvement, promote transparency, and help ensure that every child and adult affected by a cleft continues to receive safe, high-quality care.

9. What is the legal basis for CRANE collecting information?

In England and Wales, CRANE is legally allowed to collect some basic information about children born with a cleft, even if families have **not yet given consent.** This special legal permission is called 'Section 251 support' and is granted by the Secretary of State for Health and Social Care following advice from the Confidentiality Advisory Group (CAG). CAG is an independent group that checks patient data is used ethically and lawfully. In Scotland and Northern Ireland, consent is needed for CRANE to collect any information on children born with a cleft. For more information on why CRANE collects information and how the information is handled, please read our CRANE Database Information Leaflet by visiting: https://www.crane-database.org.uk/resources/information-leaflets-and-parental-consent-forms/

It is only with **consent** that CRANE can collect information on cleft-related treatments and measures of progress. Measures of progress cover growth, dental health, facial growth, speech, psychological health and wellbeing. This information is essential for CRANE to assess the standard of care provided to individuals born with a cleft. Our full data dictionary shows all data items we collect and is available at www.crane-database.org.uk

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

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

To find out more about the sources of data collected and stored, please read our Privacy Policy: https://www.crane-database.org.uk/resources/privacy-policy/.

10. How can I find out more?

If you have any questions about the CRANE Database that are not answered by our information leaflet, you can:

- Talk to a member of your local cleft team;
- Look at the CRANE website, CRANE Annual Reports or Infographics pages; and
- Contact us directly by email at crane@rcseng.ac.uk;

For personal support, community connection, and accessible information, families can also contact the **Cleft Lip and Palate Association (CLAPA)** directly on 020 7833 4883 or by email at info@clapa.com. CLAPA is the leading UK charity providing peer support, connects families, and empowers parents and patients to have a voice in cleft care.

11. Glossary

Body mass index (BMI)	The body mass index (BMI) is a widely accepted measure of weight according to height, calculated using weight in kilograms divided by the height in metres squared (kg/m^2), as per the definition of BMI by the Royal College of Paediatrics and Child Health (RCPCH). BMI was estimated for all consented children registered in CRANE with a recorded height (m) and weight (kg) at five years. These estimates were then classified into the BMI categories of underweight, normal, overweight or obese; according to the RCPCH.
Cleft Development Group (CDG)	NHS group representing all stakeholders in cleft care (including the Cleft Lip & Palate Association (CLAPA)). The CDG has overall responsibility for steering the work of the CRANE Datatabase. If you want to find out more about the CDG, please visit the **Cleft Development Group** page on our website.
Cleft lip (Source: CLAPA website)	A condition that results in an opening in the upper lip between the mouth and nose. It looks as though there is a gap in the lip. It can range from a slight notch in the coloured portion of the lip to a complete separation in one or both sides of the lip extending up and into the nose. A cleft on one side is called a unilateral cleft. If a cleft occurs on both sides it is called a bilateral cleft. A cleft in the gum may occur in association with a cleft lip. This may range from a small notch in the gum to a complete division of the gum into separate parts.
Cleft Lip & Palate Association (CLAPA)	The only UK-wide voluntary organisation specifically helping those with, and affected by, cleft lip and palate. If you want to find out more about CLAPA, please visit – http://www.clapa.com/.
Cleft palate	This occurs when the roof of the mouth has not joined completely. The back of the palate (towards the throat) is called the soft palate and the front (behind your teeth) is known as the hard palate. If you feel the inside of your mouth with your tongue, you will be able to notice the difference between the soft and the hard palate. A cleft palate can range from just an opening at the back of the soft palate to a nearly complete separation of the roof of the mouth (soft and hard palate).
Decayed, missing or filled teeth (dmft)	This is a measure of oral health and describes the total amount of tooth decay in children – specifically the total number of teeth or surfaces that are decayed (d), missing ((m), which includes teeth that do not develop and those removed due to dental disease), or filled (f). Children's scores can range from 0 to 20 for affected teeth and 0 to 88 for affected surfaces.
Five Year Old Index	An assessment used to examine dental models of the teeth in five-year-old children with a unilateral cleft lip and palate (UCLP). The index evaluates the effect of the children's cleft condition and early treatment on facial growth before later interventions, such as alveolar bone grafting or orthodontics, which may influence this growth further. Patients categorised as '1' and '2' on the index are considered to have the best possible outcomes. Children with scores categorised as '3', '4' and '5' can still have good facial growth outcomes later on in life.
Pierre Robin Sequence	A condition, also known as Robin Sequence, characterised by micrognathia (a small jaw), glossoptosis (when the tongue rests far back in the mouth, towards the throat) and breathing difficulty.
Psychosocial health	Health and wellbeing is based on the combination of both a person's thoughts and behaviours (the psychological part) and a person's social environment (the social part).
Submucous cleft palate	A submucous cleft palate (SMCP) is thought to be a subtle version of a cleft palate. There may be obvious features such as a bifid (split) uvula, a blue line in the middle of the palate (gap in the speech muscles in the palate) or notch in the hard palate. Some children may not be diagnosed with a SMCP until they are older and difficulties are noticed with their speech.