



CRANE



Promoting excellence in cleft care

CLEFT REGISTRY & AUDIT NETWORK

CRANE 2023 Annual Report:

Summary of findings for patients and parents/carers

On children born with a cleft in England, Wales, Northern Ireland and Scotland

between January 2000 and December 2022



Royal College
of Surgeons
of England



CLAPA 
Cleft Lip & Palate Association

Registered charity #212808

#1092782

Eng & Wales #1108160 & Scot #SC041034

Summary of CRANE 2023 Annual Report findings

This document will tell you about the following:

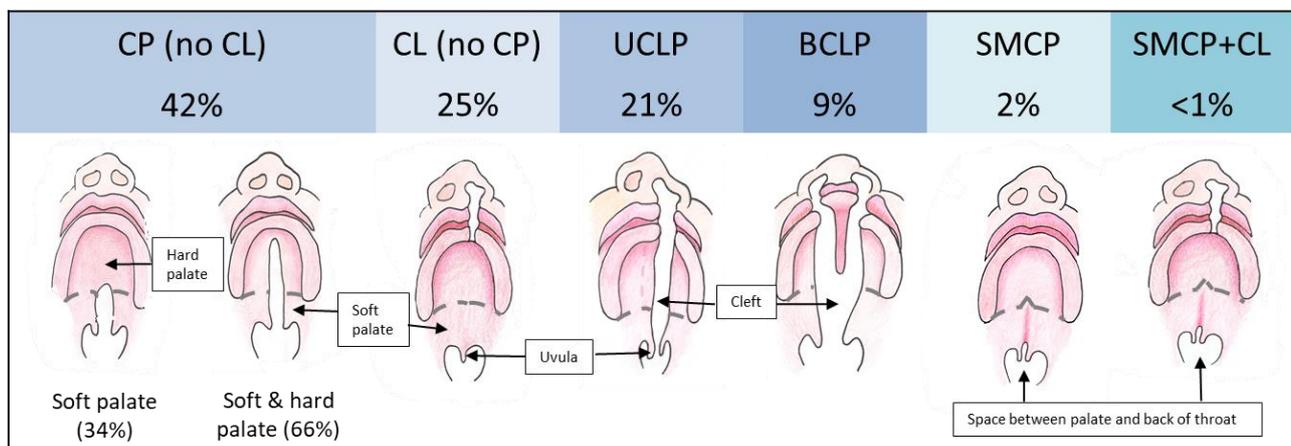
Contents

- | | |
|--|--------------------|
| 1. What is a cleft lip and/or palate? | p2 |
| 2. What is the CRANE Database? | p3 |
| 3. What other information does CRANE collect and use? | p3 |
| 4. What do we know about children with a cleft lip and/or palate registered in the CRANE Database between 2000 and 2022? | p4 |
| 5. What do we know about children born between 2020 and 2022 with a cleft? | p4 |
| 6. What do we know about 5-year-old children, born between 2014-16, with a cleft lip and/or palate? | p5 |
| 7. Learning from our most recent review of audit and health information | p5 |
| 8. How can I find out more? | p6 |
| 9. Glossary | p7 |

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

A cleft is a gap in the upper lip, the roof of the mouth (palate), or sometimes both. This is a common birth condition that can affect a number of functions including feeding, speech and hearing. Children’s dental and psychosocial health may also be affected (see the [Glossary](#) for more information on psychosocial health).

The cleft can involve part or all of the lip and/or palate. 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 (see the [Glossary](#) for more information on clefts). The percentage of children born with each cleft type can be seen in the figure below.



2. What is the CRANE Database?

The Cleft Registry and Audit Network (CRANE) Database is a national clinical **registry** that has collected information about all children born with cleft lip and/or cleft palate in England, Wales and Northern Ireland since 2000, when the database was set up by the Department of Health*. Scotland joined CRANE in 2023 so the database now covers all of the United Kingdom.

We now have records for more than 24,000 children born with a cleft. [Sections 4 and 5](#) summarise key **registry** information for children born between January 2020 and December 2022.

Typically, children with a cleft lip and/or palate benefit from cleft team care from birth into adulthood. Recording of registry information starting with diagnosis time and cleft characteristics, and then collecting information on outcomes in childhood helps to inform both the structure of current cleft care and the structure and funding of care in the future.

CRANE is also a national clinical **audit**. An audit in healthcare is used to improve the quality of care for patients affected by a particular condition. CRANE is committed to helping professionals provide the best evidence-based cleft care through the information we make available in our reports. [Section 6](#) summarises key **audit** information for 5-year-old children born between January 2014 and December 2016.

With the **informed consent** of parents/carers, CRANE collects information on:

- the care children with a cleft have received, and
- how well they are getting on in terms of their overall growth, speech, dental health, facial growth, and psychological wellbeing.

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

For more information on why CRANE collects this 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/>

3. What other information does CRANE collect and use?

With parents'/carers' consent, CRANE follows the health of children with a cleft up to age 16, by linking to their official records held by the health and education system.

This is called **data linkage**. It gives CRANE more information about the treatments that children with a cleft receive, as well as the outcomes of these treatments.

- This information is difficult to record by asking parents/carers directly or at a clinic, as this may not be easy to remember in detail (for example, the precise dates of each of their child's surgical treatments).
- Allowing CRANE to link to this information in children's official health and education records is voluntary and parents/carers and their child are free to withdraw this information from the Database at any time, without giving any reason, and without this affecting the treatment that they receive.
- For a full list of the official records that we currently link to or intend to link to, please visit the Privacy Policy: <https://www.crane-database.org.uk/resources/privacy-policy/>.

No 'data linkage' information is collected without the consent of parents/carers. Children and their families cannot be identified from CRANE's findings and publications.

If you want to find out more about the other sources of data already collected and stored about your child, please read our CRANE Database Linkage Leaflet by visiting:

<https://www.crane-database.org.uk/resources/information-leaflets-and-parental-consent-forms/>.

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

Findings from the 2023 CRANE Database report are summarised below.

4. What do we know about children with a cleft lip and/or palate registered in the CRANE Database between 2000 and 2022?

23,606

Children born between 1 January 2000 and 31 December 2022 are recorded in the CRANE Database. This means an average of 1,026 children are added each year.

896

Children born between 1 January 2022 and 31 December 2022 were added to the CRANE database.



5. What do we know about children born between 2020 and 2022 with a cleft lip and/or palate?

Consent



79% of parents/carers gave consent to the CRANE Database to collect data about their child.
2% did not consent to this.
19% had not yet confirmed.

Antenatal diagnosis

78% of children with a cleft affecting the lip were diagnosed antenatally.



Birth weight

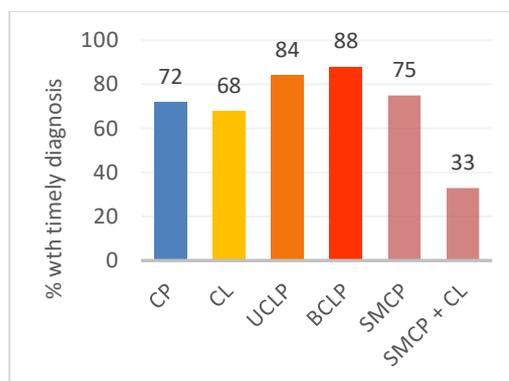
Among children born at term (≥ 37 weeks):



85% had a healthy birth weight
10% had a high birth weight
5% had a low birth weight

Timing of diagnosis

76% of babies with all cleft types (except SMCP) had their condition spotted either before or at birth[†]. Early diagnosis is important to ensure families are appropriately supported from the earliest opportunity. Cleft palate alone is rarely diagnosed prior to birth.



57% of children born with a cleft were boys and 43% were girls[‡]

82%

of children were referred by the maternity unit to a team specialising in cleft care within 24 hours of the baby being born.



94%

of parents/carers were contacted by the team specialising in cleft care within 24 hours of referral.

[†] Excluding children born with submucous cleft palate alone. Children with a cleft lip were considered to be picked up on time if they were detected antenatally. Children with a cleft palate alone were considered to be picked up on time if they were detected antenatally or at birth.

[‡] 1% of children did not have sex data specified in the CRANE database

6. What do we know about 5-year-old children, born between 2014-16, with a cleft lip and/or palate?

This section summarises information on children with a cleft at 5 years of age (born between 2014 and 2016), whose parents/carers agreed ('consented') to CRANE collecting information on their child's health.

Child growth



82%

of children born with a cleft during the birth years studied had a healthy body mass index (BMI). This means that most 5-year-olds born with a cleft had a healthy weight for their height (see the [Glossary](#) for more information on BMI).

Dental health



62%

of children had no decayed, missing or filled teeth (dmft). This is lower than the rate found in the general population (77%). This means that rates of decayed or missing teeth in children born with cleft lip and/or palate are higher than in the general population (see the [Glossary](#) for more information on dmft).

Facial growth



45%

of children with 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 – see the [Glossary](#) for more information on the index[§]). This is better than the rate reported last year (2012-2014 births) where 38% of children had good scores.

Speech



60%

of children had speech comparable to their non-cleft peers. Children with a cleft affecting only the palate tended to have better speech than those with a cleft affecting both the palate and lip.

Psychology screening



84%

of children born with a cleft, and assessed with the 'Strengths and Difficulties' questionnaires, had scores in the low/normal range, compared to 90% of their non-cleft peers. Psychologists offer support to all children as needed, including the majority of those with high scores. (see the [Glossary](#) for more information on the Strengths and Difficulties questionnaire). Furthermore, 93% of families were screened at least once before the target age of 6.

7. Learning from our most recent review of audit and health information

13 Research articles



With your data we have been able to write 13 scientific research articles, to develop the work of the audit.

This work helps to improve the way CRANE conducts and reports on audit, as well as the treatment pathways and experiences of current and future patients.

More information about this work can be found in the development section of the annual report or on the CRANE [website](#).

Continued on the next page...

[§] CRANE does not currently collect this data for children born with BCLP.

4 Presentations



We have shared our findings with healthcare professionals and patient representatives at the 2023 Craniofacial Society of Great Britain and Ireland Annual Scientific Conference.

We have also presented at each Clinical Excellence Network meeting to the healthcare professionals involved in caring for those born with a cleft.

More information about this work can be found in the development section of the annual report or on the CRANE [website](#).

Cleft affects
15/10,000 live
births



Case Ascertainment

High case ascertainment levels (accuracy of identification) in CRANE were confirmed using Office for National Statistics (ONS) and Hospital Episode Statistics (HES) data for live births.

- The overall estimate for the prevalence of cleft lip and/ or palate (CL/P) was **15.1 per 10,000 live births**, from 2009 to 2018 in England. This means that approximately 1 baby in every 660 births has a CL/P.

Based on information about children born between 2009 and 2018 in England.

3 in 4 children with a
cleft had a clear
response in both ears
on their newborn
hearing screen



Linkage to Newborn Hearing Screening Programme (NHSP) **

- For the first time, CRANE consented children born in England have been linked to the NHSP at an individual level.
- The NHSP aims to detect hearing loss as early as possible in children.
- 11,944 out of 12,566 (95%) eligible children were linked to an NHSP record.
- 98% of these children had a complete newborn hearing screen assessment.
- 76% of children had a clear response in both ears.
- Screening outcome was different depending on cleft type.

CRANE will continue to investigate why linkage rate and screening outcome was different according to cleft type.

Based on information about children born between 2006 and 2021 in England.

8. How can I find out more?

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

- Talking to a member of your local cleft team;
- Contacting us directly by phone on 020 7869 6610 or by email at crane@rcseng.ac.uk;
- Looking at the CRANE Annual [Reports](#) or [Infographics](#) pages; and
- Contacting the Cleft Lip and Palate Association (CLAPA) directly on 020 7833 4883 or by email at info@clapa.com.

** From linking to official records held by the health system with parents'/carers' consent only (as per [Section 3](#)).

9. Glossary

Body mass index (BMI)	<p>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) - https://www.rcpch.ac.uk/sites/default/files/2018-03/boys_and_girls_bmi_chart.pdf.</p> <p>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.</p>
Cleft Development Group (CDG)	<p>NHS group representing all stakeholders in cleft care (including the Cleft Lip & Palate Association (CLAPA)). The CDG is responsible for providing data for cleft births and cleft treatment for England and Wales and it endeavours, with the cooperation of the health services in Scotland and Northern Ireland, to do so for the whole of the UK.</p> <p>If you want to find out more about the CDG, please visit the Cleft Development Group page on – www.crane-database.org.uk/resources/the-cleft-development-group/</p>
Cleft lip (Source: CLAPA website)	<p>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 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.</p>
Cleft Lip & Palate Association (CLAPA)	<p>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/.</p>
Cleft palate	<p>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 (towards the mouth, 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).</p>
Decayed, missing or filled teeth (dmft)	<p>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.</p>
Five Year Old Index	<p>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.</p>
Psychosocial health	<p>Health and wellbeing based on the combination of both a person’s thoughts and behaviours (the psychological part) and a person’s social environment (the social part).</p>
Strengths and Difficulties Questionnaire	<p>An emotional and behavioural screening questionnaire for children and young people (both with and without conditions like cleft) used by psychologists to guide the care they provide to them. It asks about 25 attributes (e.g. how they interact with other children), and allows psychologists to understand whether children’s symptoms or behaviours are close to average, slightly raised, high or very high. A higher score indicates a child may need more support in certain areas.</p>
Submucous cleft palate	<p>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.</p>