CLEFT REGISTRY & AUDIT NETWORK

Promoting excellence in cleft care

CRANE 2024 Annual Report:
Summary of findings for children and parents/carers

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

Registered charity #212808

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Eng & Wales #1108160 & Scot #SC041034

Summary of CRANE 2024 Annual Report findings

This document will tell you about the following:

Contents

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, speech, hearing, dental and psychosocial health (*see the Glossary for more information on 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 (*see the Glossary for more information on clefts*).

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[*].

We have records for over 25,000 children born with a cleft since 1 January 2000. 859 children born between 1 January 2023 and 31 December 2023 were added to the CRANE database.

CRANE is also a national clinical audit. An audit in healthcare is used to improve the quality of care for people affected by a particular condition. CRANE is committed to helping professionals provide evidence-based cleft care through the information we make available in our reports.

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

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/

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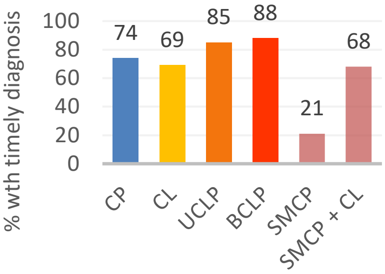
[*] CRANE is overseen and guided by the Cleft Development Group – *see the Glossary for more information on this*.

3. What do we know about CRANE-registered children who were born between 2021 and 2023?

This section summarises key registry information for the three most recent birth years. This allows a larger cohort of children to be analysed so that reliable data are presented. Recording of registry information helps to inform both the provision of current cleft care and the structure and funding of care in the future.

Antenatal diagnosis

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



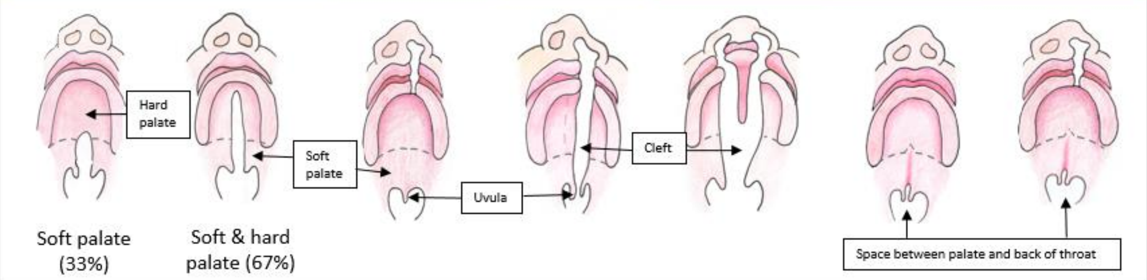
Timely diagnosis

75% of babies with all cleft types (except SMCP) had their condition diagnosed 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.

Different types of orofacial cleft

The percentage of children born with each cleft type can be seen in the figure below.

CP	CL	UCLP	BCLP	SMCP	SMCP+CL
42%	26%	21%	9%	1%	1%



23% of children with cleft palate alone were reported to have Pierre Robin Sequence, a condition characterised by micrognathia (small jaw), glossoptosis (when the tongue rests far back in the mouth, towards the throat) and breathing difficulty.

56% of babies were boys and 44% were girls.

Preterm birth

12% of babies born with a cleft were born prematurely (before 37 weeks' gestation). This compares to 8% in the general population.

82% of children were referred by the maternity unit to the regional cleft team within 24 hours of the baby being born.

95% of parents/carers were contacted by the regional cleft team within 24 hours of postnatal referral.

Consent

86% of parents/carers gave consent to the CRANE Database to collect data about their child.

3% did not consent to this.

11% had not confirmed either way.

[†] 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.

4. What do we know about 5-year-old children, born between 2015 and 2017?

This section summarises key audit information for 5-year-old children born between January 2015 and December 2017. This is only recorded for children whose parents/carers consent to CRANE collecting information on their child's health.

Age 5 is the standard time point when children with a cleft are contacted to attend a cleft clinic within the UK so that outcomes can be assessed and compared to those in other services.

Child growth

83%

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).* 4% were underweight, 10% were overweight and 5% were obese.

Dental health

62%

of children born with a cleft had no decayed, missing or filled teeth (dmft). Which means that 38% of children born with cleft did have decayed, missing or filled teeth. This is higher than the rate seen in the general population (29%) (*see the Glossary for more on dmft).*

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 – *see the Glossary for more information on the index*[‡]).

Speech

57%

of children had speech comparable to their peers without a cleft at age 5. 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

82%

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 peers without a cleft. This did not vary significantly according to cleft type.

Psychologists offer support to all children as needed but the majority of children with high scores, may need more support. (*see the Glossary for more information on the Strengths and Difficulties questionnaire).*
92% of families were screened at least once before the target age of 6.

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

5. What other information does CRANE collect and use?

With parents'/carers' consent, CRANE can link to official records held by the health and education system for children with a cleft up to age 16. This is voluntary and parents/carers and their child are free to withdraw this information from CRANE at any time, without giving any reason, and without this affecting the treatment that they receive.

Linking with other datasets is called data linkage. It gives CRANE extra information about the health of children with a cleft, their treatment, and the outcomes of treatment. It also reduces the burden of data collection on parents/carers and clinicians.

CRANE has linked with three types of records. These include 1) the Newborn Hearing Screening Programme (NHSP), which holds information about the hearing status of babies born in England, 2) Hospital Episode Statistics (HES), which holds information on the episodes of care in NHS hospitals in England, and 3) the National Pupil Database (NPD), which records educational outcomes at several time points throughout childhood for those living in England. Data linkage can allow us to explore if health outcomes and education outcomes are linked.

For more information on the official records that we currently link to or intend to link to, please visit the CRANE Database Linkage Leaflet: https://www.crane-database.org.uk/resources/information-leaflets-and-parental-consent-forms/.

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 sources of data collected and stored about your child, please read our Privacy Policy: https://www.crane-database.org.uk/resources/privacy-policy/.

Deprivation according to postcode records

- For the first time, postcodes recorded in CRANE were used to assign deprivation scores to 88% of CRANE-consented children born 2014-2023.
- We found that babies with a cleft in England were no more likely to live in the most deprived areas than babies born in the general population in England. However, the percentage of children with a cleft living in the most deprived areas varied between Cleft Services **11% to 47%**.
- This work should help clinicians, provider organisations and commissioners understand and address health inequality.

47% had satisfactory hearing in both ears on their first audiology assessment

Audiology outcomes from the Newborn Hearing Screening Programme (NHSP) [§]

- 11,574 CRANE-consented children born 2006-2021 in England were linked to the NHSP at an individual level.
- The NHSP aims to detect hearing loss as early as possible in children.
- 7,116 (61%) children had an audiology outcome recorded in their NHSP data.
- 47% of these children had satisfactory hearing in both ears.
- 38% had a hearing loss identified (with remaining 15% unknown)
- Audiology outcome was different depending on cleft type.

CRANE will continue to investigate why audiology outcome was different according to cleft type.

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

6. CRANE Database achievements

16 Research articles

CRANE has published 16 scientific research articles since 2012, to develop the work of the audit. Three of these were published in the last year.

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 children 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.

8 Presentations covering 6 cleft-related topics

We have shared our findings with healthcare professionals and people either born with a cleft or caring for a child with a cleft at the 2024 Craniofacial Society of Great Britain and Ireland Annual Scientific Conference and the European Cleft Conference in Milan.

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.

7. 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.

8. 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) - https://www.rcpch.ac.uk/sites/default/files/2018-03/boys_and_girls_bmi_chart.pdf. 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 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. 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/
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 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).
Strengths and Difficulties Questionnaire	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.
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.