



CLEFT REGISTRY & AUDIT NETWORK

## CRANE Database

Tel: 020 7869 6610

E: [crane@rcseng.ac.uk](mailto:crane@rcseng.ac.uk)

W: [www.crane-database.org.uk](http://www.crane-database.org.uk)

## 2014 Annual Report on Children with a Cleft Lip and/or Palate: Summary of Findings for Patients and Parents/Carers



Royal College  
of Surgeons  
ADVANCING SURGICAL CARE



CLAPA  
Cleft Lip & Palate Association

## Summary of 2014 CRANE Annual Report Findings

This document will tell you about the following:

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## 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 and there are 4 types of cleft: Cleft lip (CL), cleft palate (CP), one-sided clefts known as a unilateral cleft lip and palate (UCLP) and clefts that affect both sides of the lip and palate known as bilateral cleft lip and palate (BCLP) (see the [Glossary](#) for more information on clefts).

Surgery usually takes place in the first year of life. Children may have further surgery to improve their appearance and function as they grow.

Other non-surgical help and support such as speech therapy, hearing support and psychological support may also be needed by some children.

## 2. What is the CRANE Database?

The Cleft Registry and Audit Network (CRANE) database 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\*.

Typically, children with a cleft lip and/or palate need a mixture of care, from birth to adulthood, from professionals from different disciplines. This is why it is important to record information on these children at birth or at diagnosis, and into childhood to inform their care.

Specifically, CRANE collects the following information **on children of parents/carers who have given consent for this to be done:**

- The surgical treatments received by children with a cleft,
- how children with a cleft are getting on in terms of their growth (their height & weight),
- how children with a cleft are getting on in terms of their speech,
- their dental health,
- their facial growth,
- and their overall health and well-being.

CRANE is also a **national clinical audit**. An audit in healthcare is used to improve the care of patients.

CRANE is committed to helping professionals provide the best evidence-based cleft care through the information we make available in our reports.

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

**For more information on why CRANE collects this information and how the information is handled – please read our information leaflet by visit the following website – [www.crane-database.org.uk](http://www.crane-database.org.uk).**

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

The latest report on children with a cleft lip and/or palate was published in November 2014.

Main findings from that report are summarised for patients and parents/carers in the next few pages.

### 3. What we know about children born in 2013 with a cleft lip and/or palate

#### Number of children with data recorded in the CRANE database

# 1,121

This is the total number of children recorded in CRANE as born between 1 January 2013 and 31 December 2013.

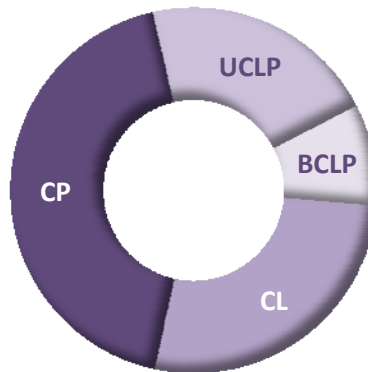
This is just a little over the average – of about 1,018 recorded per year – since CRANE records started in 2000.

These 1,121 children bring the total number of children recorded in CRANE since 2000 to **14,265**.



# 70%

Most children born in 2013 had either a cleft palate (CP (**43%**)) or a cleft lip (CL (**27%**)), accounting for 70% of children. While fewer children had either a unilateral cleft lip and palate (UCLP) or a bilateral cleft lip and palate (BCLP) – 21% and 9% respectively.

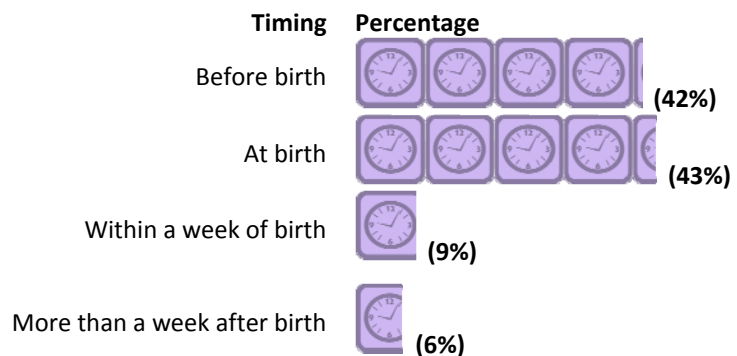


# 98%

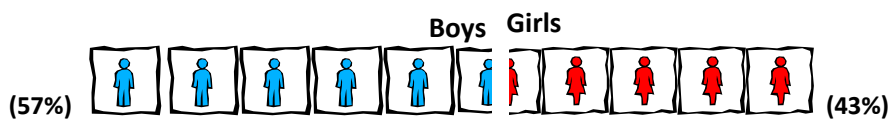
Most parents/carers approached for consent to collect data on their child in the CRANE Database had agreed to this.

#### Timing of diagnosis

Most babies with cleft had their condition spotted either before or at birth (accounting for **85%** of diagnoses). Diagnosis is very important to avoid distress for families as babies can have difficulties feeding and then gaining weight.



#### Who were these children?

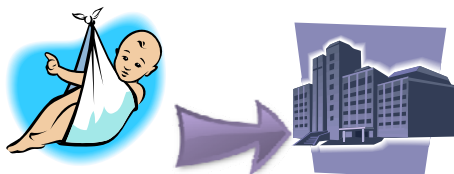


More children with a cleft lip and/or palate were boys.

## What happened next?

# 82%

The majority of children were referred by the maternity unit to a unit specialising in cleft care within 24 hours of the baby being born. This is an almost 30% improvement on last year.



# 93%

Most parents/carers were contacted by the unit specialising in cleft care within 24 hours of hearing from the maternity unit. This is an improvement of 2% since last year.

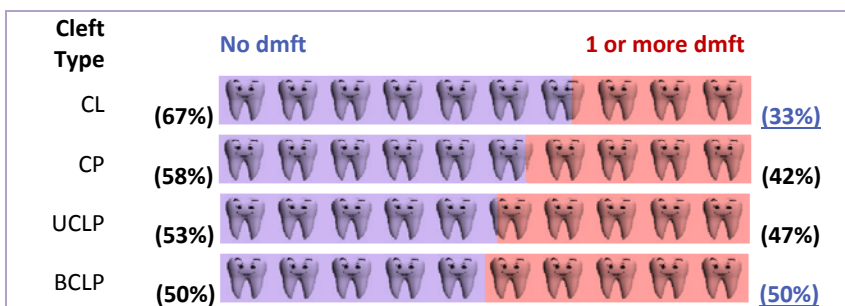
## 4. What we know about 5 year old children (born between 2004-08) with a cleft lip and/or palate

The section summarises information on children at 5 years of age (born between 2004 and 2008) – whose parents/carers have consented to information on their speech, growth, dental health and overall health being recorded in the CRANE Database.

### Dental health

# 42%

Of children had at least one decayed, missing or filled tooth (dmft), by comparison with the 39% rate found in the general population. This means rates of dmft in children born with cleft lip and/or palate are slightly higher than the general population (see the [Glossary](#) for more information on dmft).



# 50% versus 33%

Children with certain cleft types seemed to be more likely to have one or more decayed, missing or filled tooth (dmft). Such as 50% of children with bilateral cleft lip and palate (BCLP) having dmft, when compared to only 33% of children with a cleft lip (CL) with dmft.

### Facial growth



# 25%

Only a quarter of children with unilateral cleft lip and palate (UCLP) had what is known as 'poor 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 36% reported in 1998 before cleft services changed.

### Speech



# 59%

Of children had scores suggesting their speech was not significantly different from their non-cleft peer group. This means there has been improvement in rates of normal speech.

## 5. What is the impact of findings like these on children's care?

[One of our recent yearly reports](#) showed that over a quarter of babies with cleft palate had their condition missed at birth. National standards state that clefts should be diagnosed within 24 hours of birth to enable immediate referral to a specialist unit. The report warned that early diagnosis is vital to avoid distress for families as babies can have difficulties feeding and then gaining weight. The report called for national and local guidelines to be reviewed to reduce the risk of missed diagnosis of cleft palate.

As a response to our work, the Royal College of Paediatrics and Child Health (RCPCH) — in collaboration with key partners including the CRANE Database team — put together a best practice guide to help healthcare professionals to spot cleft palate in new-born babies.

This [best practice guide](#)<sup>†</sup> makes recommendations to ensure early identification of a cleft palate, and improve and standardise routine examination of babies' palate after birth (a parent/carer guide is also available).

## 6. How does CRANE plan to continue to influence children's care?

There is a lot of support and interest in finding out more about the care received by children with cleft lip and/or palate. We are looking into this further by linking CRANE data with other sources of data already collected and stored about your child.

The Cleft Lip & Palate Association ([CLAPA](#)) – **the only UK-wide voluntary organisation including parents and patients with the specific aim of helping those with, and affected by, cleft lip and palate** – endorses this type of work. Rosanna Preston, Chief Executive of CLAPA says:

*“The key to providing the best cleft care is evidence based medicine. The CRANE database is a valuable source of evidence on the incidence of cleft and on the outcomes of treatment. When CRANE is linked to other databases it increases the value of the data because it provides information about the impact of clefts across different aspects of people's lives. This means the data can be used to understand how having a cleft can affect children's educational achievement; which has been highlighted as an important area of research by patients, carers and clinicians. In fact, understanding the impact of clefts on non-health outcomes like educational achievement was voted to be the second of the ['Top 12' priorities for research in cleft lip and palate](#) with the [James Lind Alliance](#) (a priority setting partnership of patients, carers and clinicians). CLAPA endorses the linkage of data across different databases to increase our understanding of cleft lip and palate.”*

### Recent findings about educational achievement of children at 5 years of age



We were recently given permission to link with the National Pupil Database, containing information about all children in schools in England, to look at the educational achievement of children with a cleft lip and/or palate with data recorded in the CRANE Database. Initial findings suggest that children's non-cleft peers have slightly higher educational outcomes (on average) than children with a cleft. We will be exploring this further and share our findings in future reports.

<sup>†</sup> <http://www.rcpch.ac.uk/improving-child-health/clinical-guidelines-and-standards/published-rcpch/inspection-neonatal-palate>

## 7. How can I find out more?

If you have any other questions about the Cleft Registry and Audit NETwork (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](mailto:crane@rcseng.ac.uk);
- looking at the CRANE Annual Reports – available on the [Publications page](#); and
- contacting the Cleft Lip and Palate Association (CLAPA) directly on 020 7833 4883 or by email at [info@clapa.com](mailto:info@clapa.com).

## 8. Glossary

<a href="#">Cleft Development Group (CDG)</a>	NHS National group representing all stakeholders in cleft care (including the Cleft Lip & Palate Association (CLAPA)). The CDG is responsible for the CRANE Database as well as oversight and guidance on all aspects of the delivery of reorganised cleft care.
<a href="#">Cleft Lip<sup>‡</sup></a>	A condition that creates 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.
<a href="#">Cleft Lip &amp; Palate Association (CLAPA)</a>	The only UK-wide voluntary organisation specifically helping those with, and affected by, cleft lip and palate ( <a href="http://www.clapa.com/">http://www.clapa.com/</a> ).
<a href="#">Cleft Palate</a>	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) 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).
<a href="#">Decayed, missing or filled teeth (dmft)</a>	This is a measure of oral health and describes the total amount of tooth decay / dental decay or cavities 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.
<a href="#">Five Year Old Index</a>	An assessment used to examine dental models of the teeth with five-year old children with a Unilateral Cleft Lip and Palate (UCLP). The index evaluates the effects of children’s main surgery on their facial growth before any other interventions, such as orthodontics or alveolar bone grafting, which may influence this growth further. Patients categorised as ‘1’ and ‘2’ on the index are considered to have the best possible outcomes, while those categorised as ‘4’ and ‘5’ are thought to have worst outcomes in terms of facial growth (the upper jaw has not grown as far forward as the lower jaw generally), and they may benefit from further surgery to correct this once facial growth is complete.
<a href="#">Psychosocial health</a>	Health and well-being based on the combination of both a person’s thoughts and behaviours (the psychological part) and a person’s social environment (the social part).

<sup>‡</sup> Source: Cleft Lip & Palate Association website [http://www.clapa.com/medical/cleft\\_lip\\_article/107/](http://www.clapa.com/medical/cleft_lip_article/107/)