

CLEFT REGISTRY & AUDIT NETWORK

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## **2018 Annual Report on Children with a Cleft Lip and/or Palate: Summary of Findings for Patients and Parents/Carers**

**On children born in England, Wales and Northern Ireland**

**between January 2000 and December 2017**



Royal College  
of Surgeons  
ADVANCING SURGICAL CARE



**CLAPA**   
Cleft Lip & Palate Association

Registered charity #212808

#1092782

Eng & Wales #1108160 & Scot #SC041034

## Summary of 2018 CRANE Annual Report Findings

This document will tell you about the following

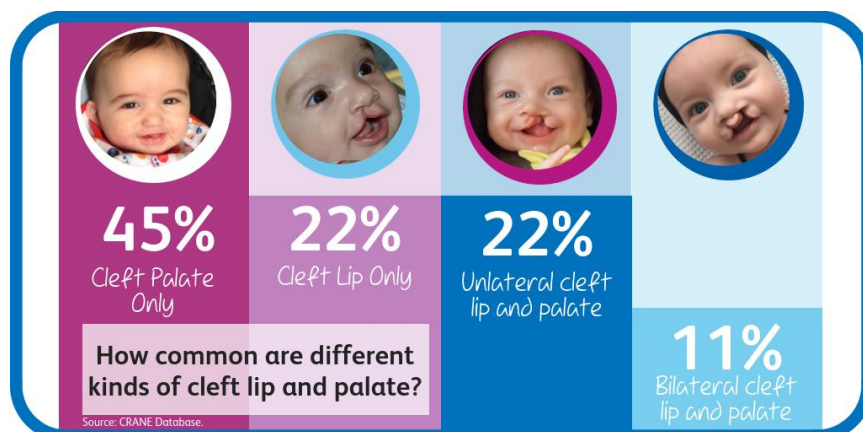
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### 1. What is a Cleft Lip and/or Palate?

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 palate (CP), cleft lip (CL), 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 cleft team care from birth to adulthood. This is why it is important to record information on these children at birth or at diagnosis, and into childhood to inform their care.

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

- 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 CRANE Database Information Leaflet by visiting – [www.crane-database.org.uk](http://www.crane-database.org.uk).

## 3. What other information does CRANE collect and use?

With parent's/carers' consent only, CRANE follows the health and education of children with a cleft by linking to their official records held by the health and education systems.

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. For example, children's educational assessments tell us about their speech, language and hearing, which may be influenced by the healthcare they receive.

- 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 records is voluntary and parents/carers and their child are free to withdraw their child's 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 and intend to link to, please visit the [Privacy Policy](http://www.crane-database.org.uk) page on – [www.crane-database.org.uk](http://www.crane-database.org.uk).

**No 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 – [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.

Main findings on children with a cleft lip and/or palate from the 2018 CRANE Database report are summarised for patients and parents/carers in the next few pages.

#### 4. What we know about children born in 2017 with a cleft lip and/or palate

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

# 1,068

This is the total number of children recorded in CRANE as born between 1 January 2017 and 31 December 2017.

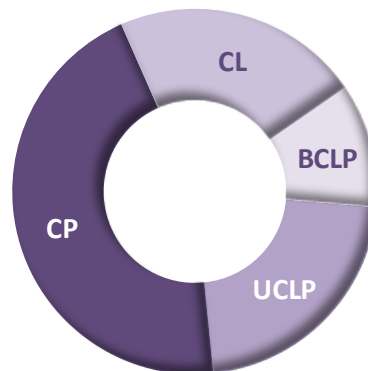
This is just a little over the average – of about 1,055 recorded per year – since CRANE records started in 2000.

These 1,068 children bring the total number of children recorded in CRANE since 2000 to **18,985**.



# 45%

Most children born in 2017 had a cleft palate (CP (45%)). Fewer children had a cleft lip (CL (22%)), a unilateral cleft lip and palate (UCLP (22%)), or a bilateral cleft lip and palate (BCLP (11%))<sup>†</sup>.

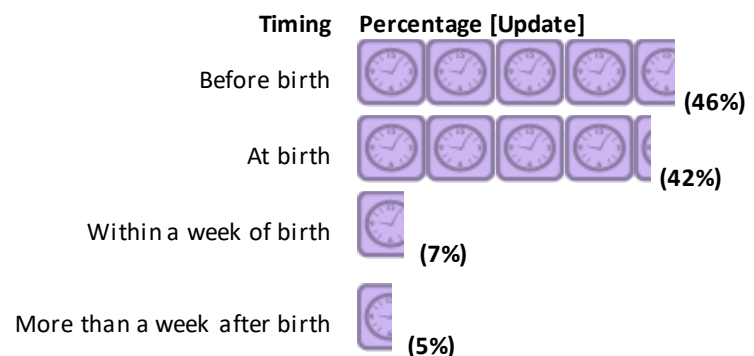


# 99%

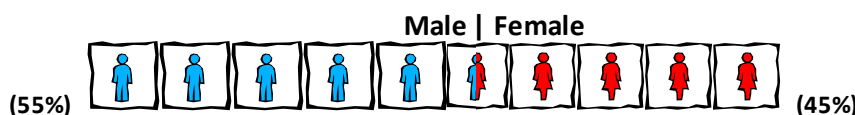
Almost all parents/carers approached for consent to collect data on their child in the CRANE Database had agreed to this.

##### Timing of diagnosis

Most babies with a cleft had their condition spotted either before or at birth (accounting for **88%** of diagnoses). Early diagnosis is very important to avoid unnecessary distress for families as babies can have difficulties feeding and then gaining weight.



##### Who were these children?



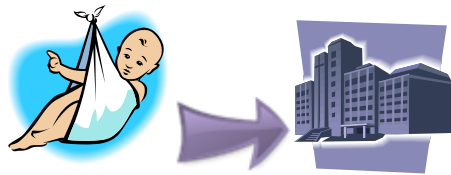
More children with a cleft lip and/or palate were male.

<sup>†</sup> The cleft type of 10% was unknown / had not been confirmed at the time of producing this report.

What happened next?

83%

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.



96%

Most parents/carers were contacted by the unit specialising in cleft care within 24 hours of hearing from the maternity unit.

5. What we know about 5 year old children (born between 2004-11) with a cleft lip and/or palate

The section summarises information on children at 5 years of age (born between 2004 and 2011) – whose parents/carers have consented to information on their speech, growth, dental health and overall health being recorded in the CRANE Database.

Dental health

41%

At least 2 in 5 children (41%) 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).

Psychology screening



15%

One in 10 of all children (10%) assessed with the 'Strengths and Difficulties' questionnaires have high or very high scores, meaning they may need extra support in certain areas. For children born with a cleft, 15% have high or very high scores\*. Psychologists offered support, as needed, for the majority of children with high scores, and to at least 1 in 5 of those with lower scores. (see the [Glossary](#) for more information on the Strengths and Difficulties questionnaire).

\*Based on information about this for 2011 births only.

Facial growth



26%

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



61%





Almost two thirds of children (61%) had scores<sup>¥</sup> suggesting their speech was not significantly different from their non-cleft peer group. This means there has been improvement in rates of normal speech.

¥Based on information about this for 2009-2011 births

## 6. Outpatient hospital appointments at 7 years of age in England

Hospital appointments can cause children to miss school, so it is important to look at how different kinds of cleft might affect a child's school life. The CRANE project looked at information on the hospital appointments of children with a cleft, collected by the National Healthcare Service (NHS) in England between 2006 and 2014. CRANE was interested in appointments for children in School Year 2, when they have their Key Stage 1 assessment and turn 7 years old. The information summarised below shows that the number and the type of hospital appointments attended by children with a cleft (and no additional medical conditions) varied by the type of cleft the child had.

### Hospital appointments in Year 2 of school (around the age of 7 years) by type of cleft

|  | CL   | CP   | UCLP   | BCLP   |
|--|--|--|--|--|
| Average number of hospital appointments                | <br>(1.2) | <br>(2.1) | <br>(2.7) | <br>(3.6) |
| % with at least 1 hospital appointment                 | 48%  | 66%  | 78%  | 85%  |
| % seeing Ear, nose and throat or Audiology specialists | 7%   | 40%  | 42%  | 43%  |
| % seeing Cleft-related surgery specialists             | 17%  | 24%  | 36%  | 44%  |
| % seeing Dental specialists                            | 20%  | 13%  | 35%  | 44%  |

The number and the type of hospital appointments for children with a cleft (and no additional medical conditions) also varied by the region in which they live. For example, 11% of children in one region had at least one dental appointment in hospital during Year 2 of school, while 48% living in a different region saw a dentist in hospital.

For more information on how CRANE uses additional data about how cleft patients are affected, for instance in school and how much they access healthcare services, see our [information leaflet](#).

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

National standards state that clefts should be diagnosed within 24 hours of birth to enable immediate referral to a specialist hospital. However, CRANE reports since 2012 show that **over a quarter of babies with cleft palate have their condition missed at birth**. We warned that early diagnosis is vital to avoid unnecessary distress for families as babies are left unable to feed and gain weight. The 2012 CRANE 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 — drafted and published [a best practice guide to help healthcare professionals identify cleft palate in newborns](#) in 2015<sup>‡</sup>.

This NICE accredited guide provides recommendations to ensure early detection of a cleft palate, and to improve and standardise the way the palate is routinely examined at birth. A parent/carer guide is also available.

The RCPCH also launched an eLearning module in 2017 entitled Cleft Palate: Examination in the Newborn. This [training module to reduce delays in detection of cleft palates](#), aims to ensure that best practice guidance for the assessment of the palate in newborns is followed consistently<sup>‡</sup>.

<sup>‡</sup> Source: Royal College of Paediatrics and Child Health (RCPCH) website – <https://www.rcpch.ac.uk/resources/palate-examination-identification-cleft-palate-newborn-best-practice-guide> and <http://rcpch.learningpool.com/course/view.php?id=291>

## 8. 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).

## 9. Glossary

|  |  |
|--|--|
| <a href="#">Cleft Development Group (CDG)</a>              | <p>NHS group representing all stakeholders in cleft care (including the Cleft Lip &amp; 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 <a href="#">Cleft Development Group</a> page on – <a href="http://www.crane-database.org.uk">www.crane-database.org.uk</a>.</p>   |
| <a href="#">Cleft Lip</a><br>(Source: CLAPA website)       | <p>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.</p>   |
| <a href="#">Cleft Lip &amp; Palate Association (CLAPA)</a> | <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 – <a href="http://www.clapa.com/">http://www.clapa.com/</a>.</p>   |
| <a href="#">Cleft Palate</a>                               | <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) 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>   |
| <a href="#">Decayed, missing or filled teeth (dmft)</a>    | <p>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.</p>  |
| <a href="#">Five Year Old Index</a>                        | <p>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.</p> |
| <a href="#">Psychosocial health</a>                        | <p>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).</p>   |
| <a href="#">Strengths and Difficulties Questionnaire</a>   | <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 a certain areas.</p>  |