



CRANE



CLEFT REGISTRY & AUDIT NETWORK

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CRANE Database Newsletter

CRANE 2018 Annual Reports Published!

Issue 2018 (4)

18 December 2018

Thank you very much for your submissions and contributions to the 2018 Annual Reports.

These can now be found in the [Publications](#) section of the [CRANE Database Website](#). Specifically:

- ◆ The full CRANE 2018 Annual Report. The Executive Summary is shown below.
- ◆ A CRANE 2018 Summary of Findings for Patients and Parents / Carers produced in collaboration with [CLAPA](#), and also published on the CLAPA website www.clapa.com. Examples of the summaries are shown below.

Data collection cut off dates for 2019 analyses

- Summer 2019 Audit Day Reports: **Friday 3 May 2019.**
- 2019 Annual Report: **Friday 28 June 2019.**

Annual Report 2018

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CRANE aims to audit, evaluate and report on the delivery of cleft services to children in England, Wales and Northern Ireland with the congenital abnormality of cleft lip and/or palate

18,985 children registered over the last seventeen years.

2017 births

All parents / carers of children born in 2017 were approached for consent. Of the families that had made their decision, 98.9% of these provided consent. This is extremely positive as consent is essential for the collection of a full dataset and the linkage to other datasets.

29.7% of children with a cleft palate received a delayed diagnosis (beyond 72 hrs after birth).

Key Findings

5-year olds: Outcomes

- Dental health** 41% of children with a cleft had at least one decayed, missing or filled tooth (D0 dmft), which is slightly higher than the rate in the general population (38.8%).
- Facial Growth** No significant relationship was found between facial growth and speech in children with a complete unilateral cleft lip and palate.
- Speech** 60% of children with a cleft had speech scores that would suggest their speech was not significantly different from their non-cleft peers.
- Psychology** 15% of children with a cleft had high or very high 'Strengths and Difficulties' scores*. This compares with 10% among their non-cleft peers.

7-year olds: Outpatient hospital appointments in England

Substantial differences exist between regions in outpatient service provision for children with a non-syndromic cleft. There are regional differences in:

- the number of annual appointments attended by patients; and
- the burden of care for relevant cleft-related specialties.

Recommendations

Clinical care

- Late diagnosis of cleft palate remains an important issue that must be addressed.
- Increased preventative dental support for children with a cleft seems essential to reduce dental decay, particularly among those at greatest risk of caries.

Outcome measures and reporting to CRANE

- Units are encouraged to continue to build on the success of 100% of parents/carers approached for consent.
- Data submission to CRANE allow the expansion of analyses, linkage to other datasets, and reporting of cleft outcomes.

Future directions

Plan for 2019

- Continue work with our stakeholders to agree important cleft-related outcomes for older children and young adults that could be assessed by measures collected by the CRANE database. A multi-phase Delphi consensus process will be used.
- Extend our work on outpatient data to determine whether the number and type of appointments are associated with educational attainment.
- Expand our reporting of cleft-related outcomes as a result of linkage to other health and education datasets.

*Scores in the 'high' and 'very high' ranges indicate a greater level of difficulties than 'low scores', classified as being in the 'close to average' range (indicating no concern).

Annual Report 2018

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45%

Cleft Palate Only

22%

Cleft Lip Only

22%

Unilateral cleft lip and palate

11%

Bilateral cleft lip and palate

How common are different kinds of cleft lip and palate?

Source: CRANE Database

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%)).

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.

Timing	Percentage (Update)
Before birth	(46%)
At birth	(42%)
Within a week of birth	(7%)
More than a week after birth	(5%)

Who were these children?

Male | Female

(55%) (45%)

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

We hope you have a lovely festive break, and wish you a happy New Year.

Please contact us at crane@rcseng.ac.uk or visit our website if you have any queries about the audit.

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