

Annual Report 2019

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.

Registrations, early care and diagnosis



20,013 children registered over the last nineteen years – from 2000 to 2018.

1,002

New registrations in 2018.



29.7% of children with a Cleft Palate (CP) received a delayed diagnosis, beyond 72 hrs after birth – from 2014 to 2018.

All parents / carers of children born in 2018 were approached for consent. Of the families that had made their decision, 99.2% 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.



Outcomes for children aged 5 years and older



Speech

61%

sychology

of children with a cleft had at least one decayed, missing or filled tooth (>0 dmft) at the age of 5 years, which is higher than the rate in the general population (31%).

of children with a cleft had at least one <u>Decayed</u>, <u>Missing or Filled</u> <u>Tooth</u> (>0 DMFT) at the age of 10 years.

of children had scores reflecting poor dental arch relationships at the age of 5 years.

No significant relationship was found between facial growth and speech among children with a complete unilateral cleft lip and palate at the age of 5 years.

of children with a cleft had speech scores that suggest their speech is not significantly different to their non-cleft peers at the age of 5 years. The proportion of children with 'normal' speech varies considerably according to cleft type.

of children with a cleft had high or very high 'Strengths and Difficulties' scores* at the age of 5 years. This compares with 10% among their non-cleft peers.



Children born with isolated clefts had lower educational attainment than children in the general population in all subject areas throughout their primary education.

Data completeness

Cleft care teams should pay particular attention to recording the following information in the CRANE Database:



- Gestational age and birth weight (47% and 48% missing data, respectively),
- weight and height at the age of 5 years (61% missing data for both measures), and
- Decayed missing and filled teeth (DMFT) at the age of 10 years (86% missing data).



*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).