

CRANE is a national registry and clinical audit. It aims to evaluate and report on the delivery of cleft services to children in England, Wales, Northern Ireland and Scotland with the congenital abnormality of cleft lip and/or palate. The registry information presented is for children born in 2020 to 2022. The audit outcomes presented are for children born in 2014-2016.

## Registry information

**23,606** children have been registered in CRANE, over the last 23 years, since 2000.

**896** children were registered in 2022.



76% of babies with a cleft were diagnosed before or within the first 24 hours after birth.



82% were referred to a cleft team within 24hrs of birth and 94% were contacted within 24hrs of referral.

### Distribution of cleft type

CP	CL	UCLP	BCLP	SMCP	SMCP+CL
42%	25%	21%	9%	2%	<1%
Soft palate	Soft & hard palate				

**81%** of families had a verified consent status, 79% consented and 2% declined consent.

## Audit outcomes at 5 years of age



### Body mass index

**82%**

of children with a cleft had a healthy BMI. 4% were underweight, 10% were overweight and 5% were obese.



### Dental health

**62%**

of children with a cleft had no decayed, missing or filled teeth (dmft=0), compared to 77% of their non-cleft peers.



### Facial growth

**45%**

of children with a complete unilateral cleft lip and palate (UCLP) had scores reflecting good dental arch relationships.



### Speech

**60%**

of children with a cleft affecting the palate had speech comparable to their peers. Children with a CP alone had better outcomes than those with a cleft affecting the lip and palate.



### Psychology

**84%**

of children with a cleft had 'Strengths and Difficulties' scores<sup>‡</sup> in the low/normal range, compared to 90% of their non-cleft peers. Furthermore, 93% of families were screened at least once before the target age of 6 years.

## Development work

### CRANE case ascertainment confirmed using ONS & Hospital Episode Statistics (HES) data

High case ascertainment levels in CRANE were confirmed using Office for National Statistics (ONS) and HES data for live births.

The overall estimate for the prevalence of cleft lip and/or palate (CL/P) was **15.1 per 10,000 live births** in CRANE, from 2009 to 2018 in England.

### CRANE - Newborn Hearing Screening Programme (NHSP) data linkage

For the first time, CRANE-consented children were linked to the NHSP at the individual-level.



Where records were linked, **98%** of children had a complete newborn hearing screening assessment.