

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 eighteen years.



Approximately 1,055 new cases are registered in CRANE per year.



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

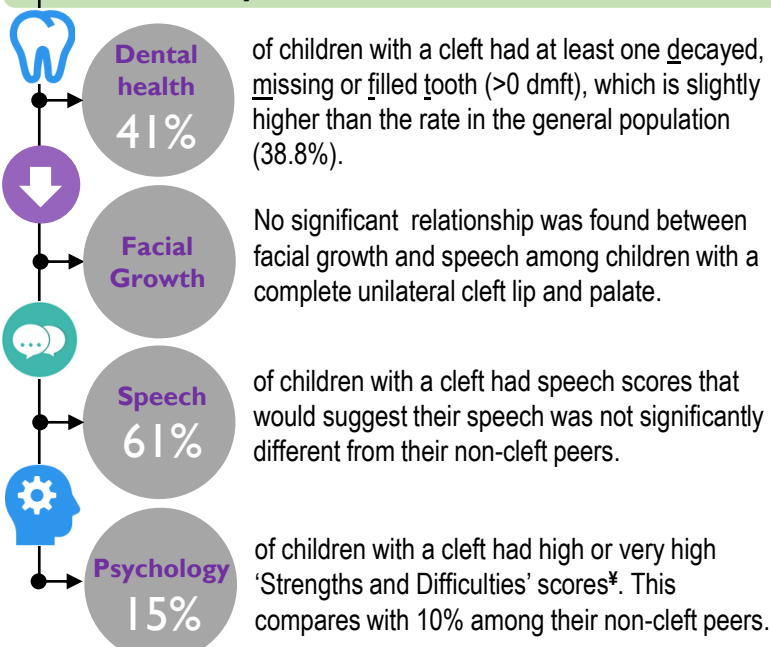
2017 births

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.



Key Findings

5-year olds: Outcomes



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).