Royal College of Surgeons of England

CLEFT REGISTRY & AUDIT NETWORK

Has your child been born with a cleft lip and/or palate in England or Wales?

What is the CRANE Database?

The **C**left **R**egistry and **A**udit **NE**twork (CRANE) is a national database that collects information about children born with cleft lip and/or palate across the UK. **Information gathered by CRANE has helped improve the care and treatment of children and families affected by a cleft.**

Why is information collected?

Improve care and treatment by highlighting and sharing best practice.

Check whether cleft care meets national standards and is consistent for every child, everywhere.

Reports are produced that let each cleft service know where they are doing well and where they can improve.

Count the number of babies born with a cleft each year.

How is the information used?

☑ Data is analysed and summarised in reports for both cleft teams and cleft service users

☑ Names or details that could identify a child are never shared publicly

☑ Quality improvement activities are run to highlight and share learnings of best practice

What information do we collect and use?

CRANE collects some identifiable registry information on children born with a cleft in England and Wales[1] without consent. This is done under 'Section 251 support' from the Secretary of State for Health and Social Care, on advice from the Confidentiality Advisory Group (CAG). CAG is an independent group that checks patient data is used lawfully and ethically.

Without consent, CRANE collects:

- NHS number*
- Patient number used in cleft centre
- Year of birth
- Year deceased (if applicable)
- Sex
- Ethnic group
- Gestational age and birthweight
- Time of cleft diagnosis
- Type of cleft condition and other diagnoses
- Name of hospital/organisation making cleft referral
- Time of first contact with cleft team

* This is a key identifier that prevents duplication and reduces the risk of missed records. It also allows us to differentiate between records and check for accuracy against clinical data.

It is only **with consent** that CRANE can collect information on cleft-related treatments and measures of progress. Measures of progress cover growth, dental health, facial growth, speech, psychological health and wellbeing, ear, nose and throat (ENT) and hearing. This information is essential for CRANE to assess the standard of care provided to individuals born with a cleft.

Our full data dictionary shows all data items we collect and is available at www.crane-database.org.uk

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[1] Information is collected under a different legal basis in Northern Ireland and Scotland.

Updated January 2026

The CRANE Database is a registry and clinical audit. It is not research, so no extra appointments or assessments are needed.

With **additional consent for data linkage**, CRANE can link at an individual level to other official national datasets:

Source	**Examples of what we learn**
Health records (Hospital and screening data)	Number of hospital visits, length of stay, additional diagnoses and treatments Early hearing status and likelihood of temporary hearing loss or permanent hearing loss by cleft characteristics
Educational/school records	Attainment levels, school absence, support provision

Examples of care improvements resulting from CRANE

CRANE found that more than 1 in 4 babies with a cleft palate had their condition missed at birth. A best-practice guide now helps healthcare professionals check the newborn palate more carefully, so that they are diagnosed as early as possible.

Using linked data, CRANE found that children born with a cleft were, historically, more likely to miss school and didn't do as well as peers at age 7. This led some cleft services to change how they schedule outpatient appointments to better support children's education.

Keeping your information safe

The CRANE Database conforms to the confidentiality rules established by the UK GDPR, the UK Data Protection Act 2018, the NHS Act 2006, and the Health and Social Care Act 2012. All personal information is handled securely and in line with legal and contractual obligations.

CRANE reports show grouped, anonymised data. We do not use any information in our reports that could be used to identify you or your child. You can see copies of our reports by visiting www.crane-database.org.uk/reports-home/.

Access to records is strictly limited to approved cleft care professionals and authorised CRANE staff, all bound by confidentiality agreements. More information on privacy can be found here.

Your choice

You can opt out of your identifiable data being shared with CRANE at any time. To opt out, contact your cleft team or CRANE at crane@rcseng.ac.uk
If you have applied for National Data Opt-Out (NDOO), you can still be included in CRANE by giving consent. Your consent will override an NDOO.

What next?

- Your Clinical Nurse Specialist can answer any questions you have.
- You will be given a CRANE consent form to read and indicate your consent wishes.

We are committed to helping healthcare professionals provide the best evidence-based care for people with cleft lip and/or palate. This is only possible because thousands of families have consented for CRANE to collect information about their child's cleft and related care. **We are very grateful to every family agreeing to share information. This helps to improve care for all children born with a cleft in the UK.**

Updated January 2026