

Has your child been born with a cleft lip and/or palate in Northern Ireland?

What is the CRANE Database?

The Cleft Registry and Audit Network ([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.



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



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



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
- No identifiable information is shared publicly
- Quality improvement activities are run to highlight and share learnings of best practice

What information do we collect and use?

CRANE collects information on all children born with a cleft in England, Wales, Northern Ireland and Scotland. In Northern Ireland, CRANE collects some identifiable information without individual consent under health legislation. This is allowed when the information is needed for important medical or public health purposes and is in the substantial public interest. All information is handled securely, used only for approved purposes, and subject to legal and ethical safeguards.

Without consent, CRANE collects the following information about your child:

- H&C/NHS number*
- Patient number used in cleft centre
- Year of birth
- Date 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.

With consent, CRANE also collects information on cleft-related treatments and measures of progress. Measures of progress cover growth, dental health, facial growth, speech, psychological health and wellbeing, ENT and audiology. 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

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 at www.crane-database.org.uk/help/privacy/.

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

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 through the information we make available in our reports and our Quality Improvement activities. 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.**