

CLEFT REGISTRY & AUDIT NETWORK

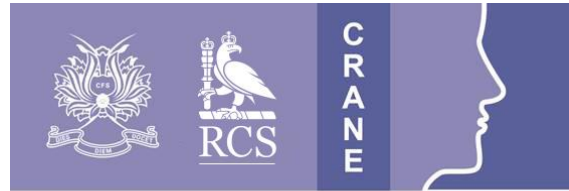
CRANE database

Parent and patient information leaflet

A guide to how we record information about children with cleft lip and cleft palate



CRANE Project Team



CLEFT REGISTRY & AUDIT NETWORK

Introduction

This leaflet describes the CRANE database and explains:

- what information we collect about children with cleft lip and palate;
- why we collect this information;
- where we collect the information from;
- the choices you have about whether organisations share information about your child with us; and
- how your child's privacy is protected.

What is the CRANE database?

The Cleft Registry and Audit NETWORK (CRANE) database collects information about children born with cleft lip or cleft palate (or both) in England, Wales and Northern Ireland. It was set up by the Department of Health to look at the quality of care for people with a cleft lip and palate. The database is funded by the National Health Service.

We, the CRANE Project Team, manage the CRANE database. We are based in the Clinical Effectiveness Unit of The Royal College of Surgeons of England (RCS) in London. We are overseen by the Cleft Development Group (CDG), a panel of people responsible for the way the database is run. This group includes the Cleft Lip & Palate Association (CLAPA), representing patients and parents.

Please visit our website for more information on this (www.CRANE-Database.org.uk).

What information do we collect?

At the time of your child's birth or diagnosis, we record:

- their name, sex and NHS number;
- their date of birth;
- their home postcode;
- details about the type of cleft they have and when it was diagnosed;
- their birth weight;
- details about other significant medical problems that might be affecting your child; and
- the hospital where your child was born and the hospital treating your child's cleft lip or palate.



As your child gets older, we collect information on surgical treatments and health outcomes. This includes information on:

- the surgical treatments they have received;
- how they are getting on in terms of their growth (their height and weight);
- their dental health and facial growth;
- how they are getting on in terms of their speech; and
- their overall health.

Why do we collect this information?

We use the information we collect in the CRANE database to:

- get an accurate picture of the number of babies born with cleft lip and cleft palate and the different types of care that are provided;
- help monitor the performance of the hospitals that treat children with cleft lip and cleft palate;

- produce reports which highlight areas of good care so that this knowledge can be shared; and
- help to find the best treatments for cleft lip and cleft palate.

We are committed to helping healthcare professionals provide the best evidence-based care for people with a cleft lip or palate through the information we make available in our reports.

How do we collect the information?

The staff in your local cleft team collect the information from your child's hospital records. They then send the information securely to the CRANE database, which we store on a secure computer system.



The system is entirely computer-based. We do not receive or hold any paper records.

We also get information from other databases and official records. We call this way of collecting information 'data linkage'. You can read more about this in the leaflet 'CRANE database: A guide to how we link to other information about children with cleft lip and cleft palate'.

How do we keep your child's information safe?

We have a very strict confidentiality and security policy. This is in line with the General Data Protection Regulation and Department of Health guidelines.

We are based at The Royal College of Surgeons (RCS) in

London. The information that we collect about your child is stored for us on a secure online computer system developed and hosted by Crown Informatics Limited, which is based in Retford, Nottinghamshire. The information is then transferred from the Crown system to a secure server at RCS for us to analyse.

The secure server is protected by a firewall and intruder-detection equipment that guards the server against access from unauthorised people outside of the project. We never carry information that identifies a child in either paper form or in electronic format on a laptop or device that identifies a child.

Only people involved in providing your child's cleft care, and a small number of staff who are directly involved in the CRANE database project, such as the research fellows, and two members of Crown Informatics Ltd, can see all the details of your child's record on the CRANE database. The research fellows need access to your child's information to analyse the data, and Crown Informatics Ltd provide the database. All the people who can access your child's record have signed contracts that make sure information about your child remains confidential. (Crown Informatics Limited provide the CRANE database with a System Level Security Policy (SLSP) in place. The SLSP is a framework to make sure that information gathered and held for the CRANE database is managed securely and effectively by the Royal College of Surgeons of England to protect patient confidentiality.)

By law, all our staff and all the Crown staff with access to CRANE records must keep all the personal information they see

confidential and secure. We must also do this under our employment contracts with the RCS.

In our reports, the information from all children in the CRANE database is added together and reported on in groups, for example, by hospital.

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 our publications page (www.crane-database.org.uk/publications).

As well as our reports, we share some information **that cannot be used to identify your child** with the following health service organisations.

- NHS England, Wales and Northern Ireland
- The Welsh Health Specialised Committee
- The Specialist Services Commissioners

For example, NHS England asks for information such as the total number of children born with a cleft lip or cleft palate, by hospital, at a particular time. They need this information for the specialised services quality dashboards, which summarise information from healthcare providers on patient outcomes (www.england.nhs.uk/commissioning/spec-services/npc-crg/spec-dashboards/).

We also share some information with other organisations that have been approved by the Cleft Development Group (see page 1). For example, every three months we update NHS England on the total number of children born with a cleft lip or palate. This helps them to provide high-quality services for these babies and their families.

You can find more information about how we share information in our CRANE database data-linkage leaflet and on our privacy policy webpage at www.crane-database.org.uk.

Can you say no to your child's information being entered into the database?

Yes, it is your choice. You can say yes or no, and we will respect your decision.



If you do not want us to collect information about the care your child receives for their cleft lip or palate, you can tell us at any time. You do not have to give a reason, and it will not affect the care that your child receives.

However, the CRANE database works best when we receive all possible information about the treatments and outcomes of every child born with a cleft lip or cleft palate. So we hope that you will agree to take part as, by doing so, this will help all hospitals improve the quality of the care they provide to patients with a cleft lip or palate, including your own child, now and in the future.

If you prefer not to take part, we will not receive any information that can identify your child. We will collect only a small amount of information about them – their NHS number, the year they were born, their sex, the type of cleft they have, which hospital is providing care relating to their cleft lip or cleft palate, information about the first contact between the hospital and your family, and date your child died (if this

applies). We collect this information as we act as a national register for cleft births.

Once your child reaches 16 years old, they can decide whether they want us to keep information about them.

You or your child, if they are 16 or older, can contact us at any time to change your decision to let us collect information about the care your child receives, or to carry out data linkage with information about your child. Our contact details are on the last page of this leaflet.

How long do we keep the information?

The treatment of your child's cleft lip or cleft palate can take many years, continuing into adulthood. We will collect information up to your child's 16th birthday. In line with the NHS Records Management Code of Practice for Health and Social Care 2016, for records of long-term illness, we will keep your child's health records up to their 46th birthday. For more information visit www.digital.nhs.uk/data-and-information/looking-after-information/data-security-and-information-governance/codes-of-practice-for-handling-information-in-health-and-care/records-management-code-of-practice-for-health-and-social-care-2016 .



Can you see the records on the database?

Yes, you can ask to see a copy of the information we have about your child. You can also ask us to change or remove any inaccurate information. This also applies to your child, if they want to see their records after their 16th birthday.

How has the CRANE database been used to improve children's care so far?

An example of how the information we collect has been used to improve children's care so far is that a few years ago, information on our database identified that over a quarter of babies with a cleft palate had their condition missed within the first 24 hours of birth. So these babies were not immediately referred to a specialist unit. This caused unnecessary distress for families, as babies with a cleft palate can have difficulties feeding and then gaining weight.

As a response to this, the Royal College of Paediatrics and Child Health (RCPCH) worked with key partners (including us) to put together best-practice guidance to help healthcare professionals to spot cleft palate in newborn babies. (You can read this guidance on the resources page of the RCPCH website at www.rcpch.ac.uk)

Because of our report, fewer babies with a cleft palate will be missed at birth.

Our commitment to you and your child

- Allowing us to collect information about the care your child receives for their cleft lip or palate is voluntary and you and your child are free to withdraw your child's information from the database at any time, without giving any reason, and without this affecting the treatment that they receive.



- Neither you nor your child will be identified from our findings and publications.
- In the same way the clinicians who provide your child's care must keep your child's information confidential, we must also keep your child's information confidential.
- There is an independent panel – the Cleft Development Group – whose job it is to look at what we do and how we do it to make sure your and your child's rights are protected. For example, they make sure that all analyses of your child's information meets the highest ethical and scientific standards.
- All our work is to benefit the care that patients receive for their cleft lip or palate, and is not for profit.

How can you find out more?

If you have any questions about the CRANE database, you can get more information by talking to a member of your local cleft team or by visiting our website at www.crane-database.org.uk .

You can write to us or call us using the following details.

CRANE Database
Clinical Effectiveness Unit
The Royal College of Surgeons of England
35-43 Lincoln's Inn Fields
London
WC2A 3PE

Phone: 020 7869 6610

Email: crane@rcseng.ac.uk

If you have any general questions about cleft lip and palate, you can get more information by talking to:

- a member of your local cleft team; or
- the Cleft Lip and Palate Association (CLAPA).

Phone: 020 7833 4883

Email: info@clapa.com

Website: www.clapa.com



What happens next?

- A member of the cleft team will ask you to sign a consent form to record whether you are happy for us to enter information about your child's cleft lip or palate onto the database.
- You will be able to make your decision about each type of data linkage separately.

