



CLEFT REGISTRY & AUDIT NETWORK

CRANE database

Parent and patient information leaflet

A guide to how we link to other official records about children with cleft lip and cleft palate



CRANE Project Team



CLEFT REGISTRY & AUDIT NETWORK

Introduction

This leaflet explains how we collect information from other databases and official records. This way of collecting information is called 'data linkage'.

We describe:

- why we link to other databases and records;
- the records we currently link to and those we plan to link to in the near future;
- the choices you have about whether information about your child is linked to other databases; and
- how we protect your privacy.

Why do we link to other official records?

With your agreement, we would like to follow your child's health and education by linking to their official records held by the health and education systems.

Data linkage gives us more information about the treatments that children with a cleft lip or palate receive, as well as the outcomes of these treatments. For example, children's educational assessments tell us about their speech and language, which may be influenced by the healthcare they receive.

Linked data can be used to spot gaps in healthcare provision and, in terms of education, gaps in extra support that may benefit children with a cleft lip or palate. This type of information is not available to your local cleft team.

Linkage between the CRANE database and other records

The official records that we currently link with include the following. There are more details of these records on the privacy policy page of our website at www.crane-database.org.uk/.

| Records | Organisation | Information we collect |
|--------------------------------------|--------------------------------|--|
| Hospital Episode Statistics | NHS Digital | When people go to hospital, how long they spend in hospital, diagnoses and treatment. |
| Patient Episode Statistics for Wales | Wales Information Centre | When people go to hospital, how long they spend in hospital, diagnoses and treatment. |
| Death register | Office for National Statistics | Date and cause of death. |
| National Pupil Database | Department for Education | Information from all state-maintained schools in England, including information about the population, social and economic factors, school attendance, school attainment and special educational needs. |

Records that we aim to link with in the near future

| Records | Organisation | Information we will collect |
|-------------------------------------|--------------------------------|--|
| Newborn Hearing Screening Programme | Public Health England | Outcome of the hearing screening which most babies in England have within four to five weeks of birth. |
| Dental data | NHS Business Service Authority | Information about the access children with a cleft lip or palate have to routine dental care, from dentists outside of hospital. |

How do we link to other records?

We carry out data linkage by sending limited identifiable information about your child to the organisation holding the official records. The identifiable information we pass on includes their name, date of birth and postcode. If we are linking to NHS records, we also include your child's NHS number to make sure there is a correct match between records. We will not pass on any other information.

Data linkage works best if your child's personal details are kept up to date. Around once a year, we will ask the central NHS administrative databases, through the NHS Digital Personal Demographics Service

(www.digital.nhs.uk/services/demographics), to check that we hold an up-to-date postcode for your child. To do this, we share details of your child's postcode, NHS number and sex. NHS Digital then send us details of any postcodes they have on file for the family. This helps us keep your child's records up to date and match to other records that we link to.

For the latest information on the official records we are planning to link to, please visit our website (www.CRANE-Database.org.uk).

Can you say no to one or all data-linkage options?

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



You will be able to make your decision about each type of data linkage separately when you fill in the consent form.

However, the CRANE database project works best when we receive all possible information about the treatments and outcomes of every child born with a cleft lip or cleft palate. We hope that you will agree to take part in data linkage as, by doing so, this will help all hospitals improve the quality of the care they provide to those 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 share any information about your child and we will not link to other official records held about your child.

Once your child is old enough, they can decide whether they want information in other official records to be linked to the information we hold.

You or your child can contact us at any time to change your decision about data linkage. You do not need to give a reason for changing your decision, and it will not affect the care that your child receives. Our contact details are listed 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 information we have collected through links with other records?

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.

When your child is older, they may ask to see a copy of their record. They are very welcome to do so using the details on our website (www.crane-database.org.uk).

How do we you 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.

Only people involved in providing care relating to your child's cleft lip or cleft palate, 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 Ltd 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).

Our commitment to you and your child

- Allowing us to link information about the care your child receives for their cleft lip or palate to their official records 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 as 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 is checked to make sure it 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 our data-linkage work, you can get more information by visiting our website at www.crane-database.org.uk.

You can also 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 cleft palate onto the database.

- You will be able to make your decision about each type of data linkage separately.

