

CRANE Database Q&A session

23 February 2026

Kate Fitzsimons & Samriddhi Sharma
On behalf of the CRANE Database team

Overview

1. Welcome and introductions
2. Database updates
3. Data submission deadlines
4. Data requirements
5. How to check and update data
6. Quality Improvement (QI) resources
7. Questions

1. Welcome and introductions

Any new members of staff?

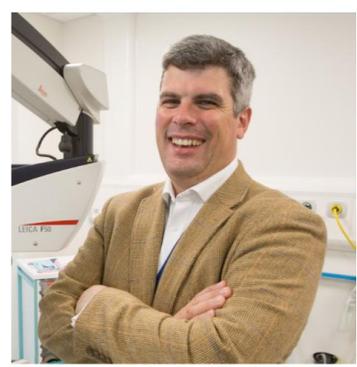


CRANE

- Based in the Clinical Effectiveness Unit at the **Royal College of Surgeons of England**
 - Separate organisation to NHS so when sharing pt information – use CRANE ID only
- **Set up in 2000** in response to the 1998 Clinical Standards and Advisory Group (CSAG) report, which exposed major issues in UK cleft care
- **UK wide:** Northern Ireland joined officially in 2016 and Scotland in 2023
- **Registry** for all children born alive with cleft lip and/or palate in the England, Wales & Northern Ireland
 - Section 251 approval to collect registry information without parental consent
 - Scotland requires consent
- **Audit** of clinical care and outcomes from diagnosis to age 10
 - Parental consent required to collect outcomes throughout childhood (~90% of all registrations, 97% of those with verified consent status)
 - Additional consent required to link to external datasets



Small team



Craig Russell
Clinical Project Lead
Consultant Cleft, Plastic and
Reconstructive Surgeon, NHS
Greater Glasgow and Clyde



Kate Fitzsimons
Senior Research Fellow,
Clinical Effectiveness Unit, RCS



Samridhi Sharma
CRANE Coordinator
Clinical Effectiveness Unit, RCS



Abhishek Dixit
Data Manager/Data Scientist,
Clinical Effectiveness Unit, RCS

2. Updates

Organisational Audit Report (July 2025)

- Published July 2025
- Teams asked to reflect on care during 2024
- 100% of services responded
- Considerable variation in commissioned services, staffing levels and access to facilities.
- Workforce shortages & recruitment challenges are widespread (psychology, orthodontics & dentistry)
- Equitability of access is challenging (SLT & dentistry)
- Services reported high levels of engaged with CRANE and value its role in quality improvement.



Cleft Registry and Audit NETWORK Database

Organisational Audit Report

An Organisational Audit of services providing care to children born with a cleft lip and/or palate in England, Wales, Northern Ireland and Scotland

Published 18 July 2025
On behalf of NHS England and the Cleft Development Group

2025 Annual Report

- Published December 2025
 - Key findings & recommendations
 - Registry information
 - Consent verification
 - 5-year outcomes
 - Summary of organisational audit
- Infographic
- Supplementary tables
- Outlier responses
- Summary for cleft community



Promoting excellence in cleft care

CLEFT REGISTRY & AUDIT NETWORK



Cleft Registry and Audit Network Database

Part of the Clinical Effectiveness Unit, of the Royal College of Surgeons of England

2025 Annual Report

Results of the registry and audit for children born with a cleft lip and/or palate in England, Wales, Northern Ireland and Scotland

On behalf of the Cleft Development Group



Annual Report 2025

CRANE is a national registry and clinical audit. It evaluates and reports on the delivery of cleft services to children born with a cleft lip and/or palate in England, Wales, Northern Ireland and Scotland. Registry information is presented for children born in 2022-2024 and audit outcomes at 5 years of age are presented for children born in 2016-2018.

Registry information

25,862 children have been registered since CRANE started in 2000.

901 children were born with a cleft in 2024.

78% of babies with cleft lip were diagnosed antenatally, while 74% of babies with cleft palate alone were diagnosed within 24hrs of birth.

82% were referred to a cleft team within 24hrs of birth and 97% were contacted within 24hrs of referral.

Distribution of cleft type

CP	CL	UCLP	BCLP	SMCP	SMCP+CL
43%	26%	20%	9%	<2%	<1%

90% of families had a verified consent status, 97% consented and 3% declined consent.

Audit outcomes at 5 years of age

Body mass index

84% of children with a cleft had a healthy BMI. 4% were underweight, 8% were overweight and 5% were obese.

Speech

54% of children with a cleft palate (+/-cleft lip) had speech comparable to their peers.

74% achieved speech without evidence of structurally-related speech difficulties.

62% achieved speech without cleft-related speech characteristics that may require therapy or surgery.

Speech varies according to cleft type.

Dental health

61% of children with a cleft had no decayed, missing or filled teeth. This compares to 71% of their non-cleft peers.

Facial growth

54% of children with a complete unilateral cleft lip and palate (UCLP) had scores reflecting good dental arch relationships.

Psychology

92% of children were seen by a psychologist. A psychological screen was completed or psychological input arranged if needed.

Development work

Organisational Audit Report

100% of cleft services responded to the first comprehensive organisational audit (OA) of cleft care since the CSAG report in the late 1990s. The OA findings highlight considerable variation in commissioned services, staffing levels, and access to diagnostic and operative facilities. A well-resourced and consistent model of cleft care delivery is required in the UK.

Conference Presentations

CRANE was involved in **7** different presentations across both the 15th International Congress of Cleft Lip/ Palate and Related Craniofacial Anomalies (**CLEFT2025**) in Japan and the Craniofacial Conference (**CFSGBI 2025**) in Newcastle.

We value sharing our findings with health professionals and patient representatives.

For further information visit www.CRANE-Database.org.uk

New CRANE information leaflets



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 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
- 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* 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](http://www.crane-database.org.uk) shows all data items we collect and is available at www.crane-database.org.uk

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

Updated January 2026



CLEFT REGISTRY & AUDIT NETWORK

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

Health records
(Hospital and screening data)

Examples of what we learn

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

Click on the links below to download the CRANE Database Information Leaflets for families living in Northern Ireland and Scotland:

[CRANE Database Information Leaflet \(Northern Ireland\)](#)

[CRANE Database Information Leaflet \(Scotland\)](#)



CRANE information for families



CLEFT REGISTRY & AUDIT NETWORK

New consent forms



CLEFT REGISTRY & AUDIT NETWORK

CRANE Consent form (England and Wales)

Recording information about your child in the CRANE Database

A member of the cleft team should have given you the CRANE Database information leaflet: **"Has your child been born with a cleft lip and/or palate?"** You should read this leaflet and ask any questions you have before signing this form. There is more information on our website at www.crane-database.org.uk

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

To complete this pdf form electronically, open the document using an Acrobat Reader PDF software and click on the fountain pen icon, which should appear at the top of the document, as part of the toolbar. Hover over the boxes for ticking and then sign your name at the end.

1. The CRANE Database

Please give your child's name (here): _____

Do you agree to the CRANE Database collecting information related to your child's cleft lip and/or cleft palate treatments and measures of progress? **Tick one box** Yes No

2. Data linkage to access other information in official records

I understand that my child's details, including their name, date of birth, postcode and NHS number, may be used to link to their official records (listed below) to collect more information for use by the CRANE Database.

Tick one box Yes No

2.1. **Health records:** Do you agree to CRANE linking to your child's information held by the National Health Service (NHS) databases and records, the Office for National Statistics (ONS), and NHS England (or its successor body)?

Tick one box Yes No

2.2. **Education records:** Do you agree to CRANE linking to your child's information held by the Department for Education (DFE)?

Tick one box Yes No

A list of the databases and records we link to is available on the [Privacy Policy](#) page of our website.

4. I confirm that:

- I have read the information leaflet about the CRANE Database and understand it.
- I have been given the chance to ask a member of the cleft team questions about the CRANE Database.
- I understand that I can choose for information about my child's care not to be recorded in the CRANE Database and that I am free to withdraw my child's information from the database at any time, without giving any reason and without this affecting the treatment that they receive.
- I know who to contact if I change my mind and want my child's information withdrawn from the CRANE Database.
- I understand that any information about my child will be kept confidential and used for the CRANE Database only.

Name of parent or legal guardian

Date

Signature

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

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.

3. Ethnic group

Tick one box.

White

- White British
- White Irish
- Any other White background

Mixed/ Multiple ethnic groups

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other Mixed/ Multiple ethnic background

Asian/ Asian British

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background

Black/ African/ Caribbean/ Black British

- African
- Caribbean
- Any other Black/ African/ Caribbean background

Other ethnic group

- Arab
- Any other ethnic group



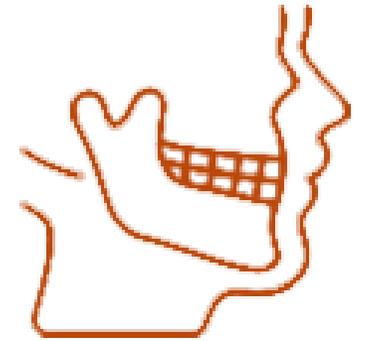
Gestational age and birthweight

- Now open to all registrations, not just consented cases.
 - CAG approval covering England and Wales. NI to follow too.
- Submit data for all cases born in 2026 onwards
 - We are requesting an amendment to apply this change retrospectively
- Added '**+ days**' to gestational age. It was previously whole weeks.
- Moving to '**Patient details**' tab from 'Outcomes' tab
- We can verify our early findings that babies with cleft likely to be:
 - Born premature
 - Born with low birthweight



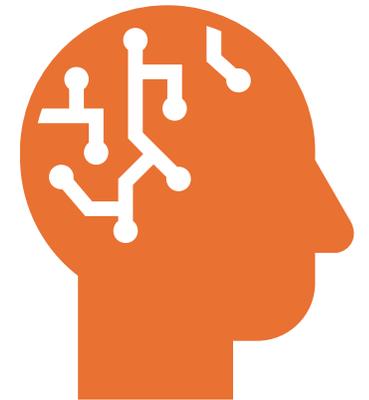
5-year-old index

- Now open to complete BCLP cases (LAHSAL)
- Data can be entered retrospectively and in bulk using imports
- Dr Susana Dominguez-Gonzales (Liverpool) has scores for cases going back to 2005.
- CRANE will support entry of retrospective cases.



Cleft Q & TIM at 10y (psychology outcome)

- CRANE working with Psychology CEN
- There will be separate Cleft Q & TIM tabs under 10-year outcomes section on database.
- Psychological and Social Functioning sub-scales to be submitted
 - 10 questions for each subscale (each rated 1 'never' to 4 'always')
- Cleft Q data fields should be open by May 2026
- Data can be entered retrospectively and in bulk (imports)



Surgical timings (under consideration)

- **Lip**
 - Date of 1st primary lip adhesion/repair
 - Date definitive lip repair
- **Palate**
 - Date of 1st primary palate repair
 - Date primary palate repair complete
- **Speech surgery**
 - Date of 1st surgery for speech purposes
 - Date of 2nd surgery for speech purposes



Data requirements

Any Questions

3. Data submission deadlines

Details on Milestones web page

Cleft Registry and Audit Network (CRANE) TIMELINE 2026

The graphic below outlines the timeline that CRANE will work to in 2026.

Key data submission deadlines are flagged. These include those for the quarterly Specialised Services Quality Dashboards. For more information on the SSQD visit <https://www.crane-database.org.uk/resources/specialised-services-quality-dashboard-indicators-submitted-by-crane/>.

The final draft of the CRANE Annual Report will be agreed by key stakeholders, including the Cleft Development Group (CDG), before publication in December 2026.

KEY

Review/update CRANE records

Webinars

Data extracts

CRANE analyses

Outlier process

CDG review

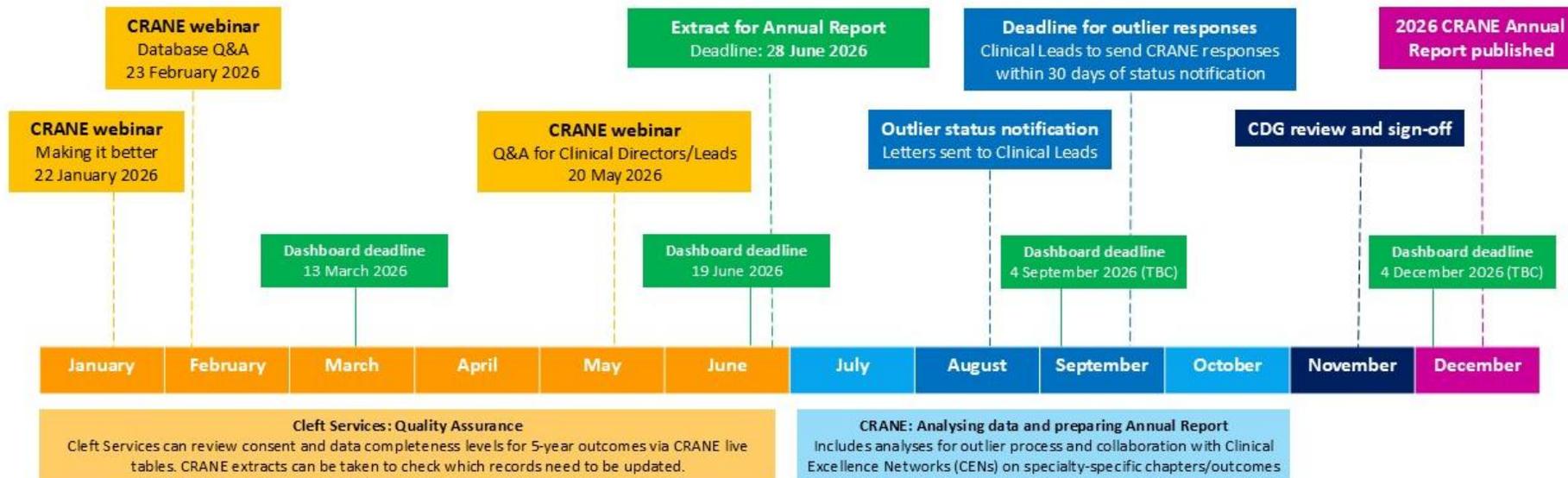
Publication

Eligibility for 2026 Annual report

Registry: Births 2023-2025

5-year outcomes: Births 2017-2019

Data Collection Milestones for 2026 - CRANE Database



2025 data submission deadlines

Annual Report deadline:

- Sunday 28 June 2026 – Annual report extract taken on 29 June
 - Registrations for 2023 to 2025 births
 - 5-year outcomes for 2017 to 2019 births
- Outlier policy letters sent to Clinical Directors: **August - Response deadline end September**

Dashboard deadlines:

- Friday 13th March 2025 – Q3 2025/26 (CLP00, CLP01, CLP02: registrations, antenatal contact, CNS visit within 24h of postnatal referral)
- Friday 19th June 2025 – Q4 2025/26 (CLP00, CLP01, CLP02, CLP05, CLP06, CLP09: registry + 5-year-old outcomes)

<https://www.crane-database.org.uk/resources/specialised-services-quality-dashboard-indicators-submitted-by-crane/>



4. Data requirements

Data Dictionary & Data Collection Forms

CRANE Data Dictionary & Data Collection Forms

Click on the image below to download your copy of the CRANE Data Dictionary



Item Name	Description	Notes
1. gender	As information consented.	
1.1. sex	As information consented.	Report only if recorded for 4 for 'sex' (Males/Females/Other/Not stated)
1.1.1. sex	As information consented. This field requires capture future ages.	NOT for patient in CRANE extra health data
1.1.2. sex	As information consented. This field requires capture future ages.	NOT for patient in CRANE extra Education data
1.1.3. sex	As information consented. This field requires capture future ages.	NOT for patient in CRANE extra Education data
1.1.4. sex	As information consented. This field requires capture future ages.	NOT for patient in CRANE extra Education data
1.1.5. sex	As information consented. This field requires capture future ages.	NOT for patient in CRANE extra Education data
1.1.6. sex	As information consented. This field requires capture future ages.	NOT for patient in CRANE extra Education data
1.1.7. sex	As information consented. This field requires capture future ages.	NOT for patient in CRANE extra Education data
1.1.8. sex	As information consented. This field requires capture future ages.	NOT for patient in CRANE extra Education data
1.1.9. sex	As information consented. This field requires capture future ages.	NOT for patient in CRANE extra Education data
1.1.10. sex	As information consented. This field requires capture future ages.	NOT for patient in CRANE extra Education data
1.1.11. sex	As information consented. This field requires capture future ages.	NOT for patient in CRANE extra Education data
1.1.12. sex	As information consented. This field requires capture future ages.	NOT for patient in CRANE extra Education data
1.1.13. sex	As information consented. This field requires capture future ages.	NOT for patient in CRANE extra Education data
1.1.14. sex	As information consented. This field requires capture future ages.	NOT for patient in CRANE extra Education data
1.1.15. sex	As information consented. This field requires capture future ages.	NOT for patient in CRANE extra Education data
1.1.16. sex	As information consented. This field requires capture future ages.	NOT for patient in CRANE extra Education data
1.1.17. sex	As information consented. This field requires capture future ages.	NOT for patient in CRANE extra Education data
1.1.18. sex	As information consented. This field requires capture future ages.	NOT for patient in CRANE extra Education data
1.1.19. sex	As information consented. This field requires capture future ages.	NOT for patient in CRANE extra Education data
1.1.20. sex	As information consented. This field requires capture future ages.	NOT for patient in CRANE extra Education data

This document (above) provides information on all data items collected by the CRANE Database.

Last updated July 2022:

- The Database started collecting data on Developmental Defects of Enamel (DDE) at 5 and 10 years of age, dental health outcome information, in May 2022. Corrections to the information for this section were made in July 2022.

The data collected by the CRANE Database is also detailed in CRANE Data Collection Forms on:

- Patient registration (Form 1), and outcomes (Form 2). These are available to download below.

[Download Form 1 – Patient registration](#)

[Download Form 2 – Outcomes](#)

Docs updated to reflect database changes

- Notified by newsletter, webinars & email.

Do you create your own forms?

- How do you keep them aligned/updated?

New updates will reflect changes:

- Birthweight
- Gestational age
- Five year old index for BCLP
- Cleft Q
- TIM scores at 10y

<https://www.crane-database.org.uk/resources/crane-data-dictionary/>

CRANE reports & supplementary tables

- Tables / Figures presented - calculated using valid data as denominators
- Subject to the usual inclusions and exclusions

Cohort summary	
Data source	The CRANE Database. Extract taken: 30 June 2025
Birth years	Three years: 2022 to 2024
Countries	England, Wales, Northern Ireland and Scotland
Inclusions	CRANE-registered children ⁹ , including those without a specified cleft type and those with a submucous cleft palate, unless stated otherwise.
Exclusions	None, unless stated otherwise.
Notes	<ul style="list-style-type: none">• Not subject to outlier policy but funnel plots provided to demonstrate variation in rates across services.• Data are not risk adjusted.
Legal basis for data collection	<p>The data used for this section are collected for all registered cases under a 'Section 251' exemption (of the NHS Act 2006 and its current regulations, the Health Service (Control of Patient Information (CPI)) Regulations 2002), with approval from the Confidentiality Advisory Group (CAG) for the disclosure of CPI held by the CRANE Database.</p> <p>Gestation and birthweight are exceptions to the Section 251 exemption and are collected only for children whose families have given informed consent to outcomes data collection by the CRANE Database.</p>

[CRANE Database 2025 Annual Report - CRANE Database](#)

Data issues to address

- **Dental data**

- Missing postcode (West Midlands, Cleft Net East & Spires: Prioritise 2017-2019 births)
- Missing LAHSAL information (West Midlands)

- **Speech data**

- Cleft details
 - Missing Submucous (No/Yes) (West Midlands)
 - Simonart's bands – sometimes this can be missing
- VP surgery/fistula repair boxes must be ticked (No/Yes).
- Syndrome information must be ticked (No/Yes-named/Yes, unknown name)
- Sex

- **Transfers into service**

- Submit data – these cases will be analysed separately.



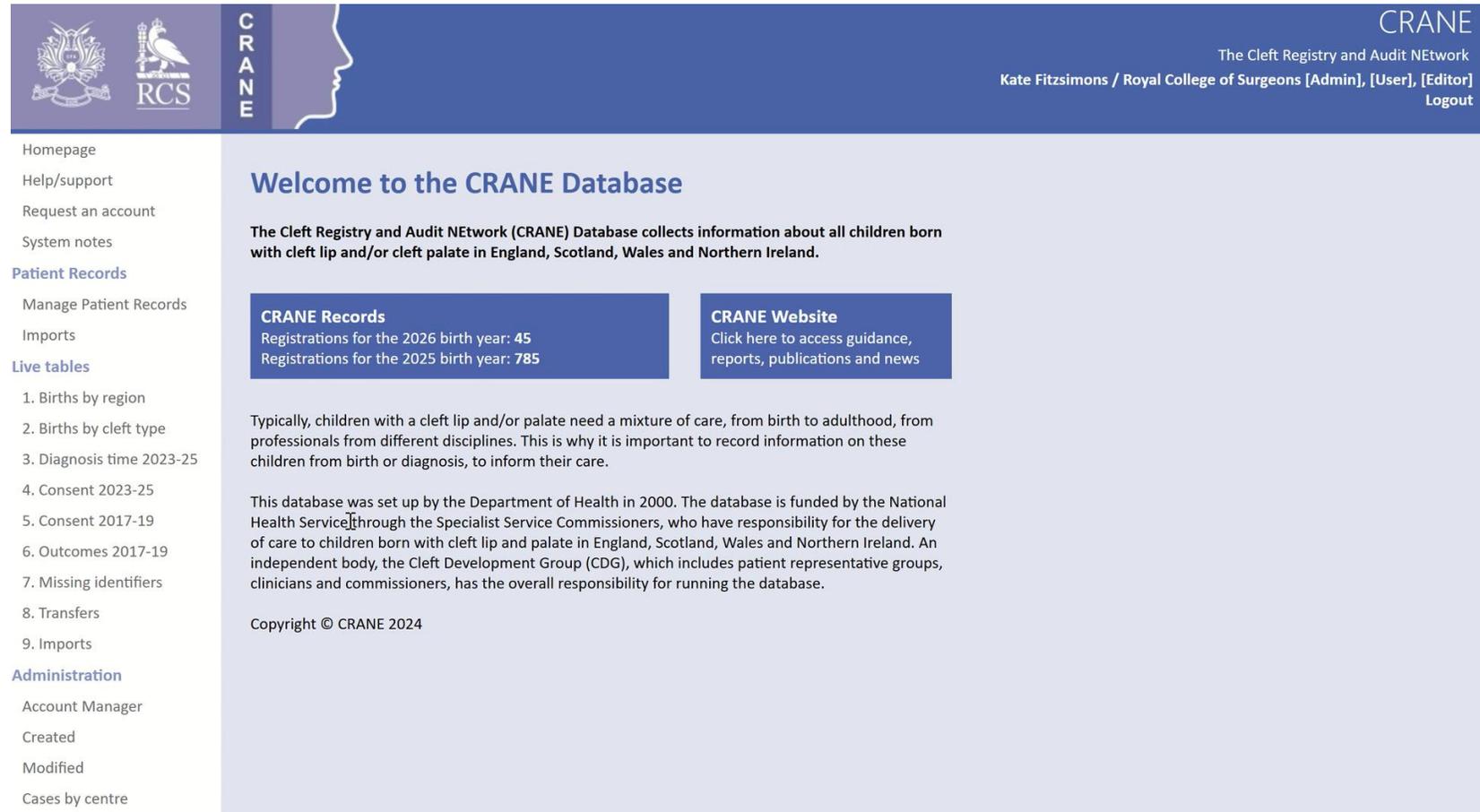
Data requirements

Any Questions

5. How to check and update data

Database access

- New process introduced (Feb 2025)
- Cleft team member with existing access can request
- Clinical Lead will be notified automatically and they can approve request.
- Access will be granted and username/pw sent.
- CRANE will be notified by email so records can be updated.



The screenshot shows the CRANE Database website interface. At the top, there is a navigation bar with the CRANE logo (The Cleft Registry and Audit Network) and user information: Kate Fitzsimons / Royal College of Surgeons [Admin], [User], [Editor], Logout. Below the navigation bar is a sidebar menu with the following items: Homepage, Help/support, Request an account, System notes, Patient Records (Manage Patient Records, Imports), Live tables (1. Births by region, 2. Births by cleft type, 3. Diagnosis time 2023-25, 4. Consent 2023-25, 5. Consent 2017-19, 6. Outcomes 2017-19, 7. Missing identifiers, 8. Transfers, 9. Imports), Administration (Account Manager, Created, Modified, Cases by centre). The main content area is titled "Welcome to the CRANE Database" and contains the following text: "The Cleft Registry and Audit Network (CRANE) Database collects information about all children born with cleft lip and/or cleft palate in England, Scotland, Wales and Northern Ireland." Below this text are two blue boxes: "CRANE Records" (Registrations for the 2026 birth year: 45, Registrations for the 2025 birth year: 785) and "CRANE Website" (Click here to access guidance, reports, publications and news). Below these boxes is a paragraph: "Typically, children with a cleft lip and/or palate need a mixture of care, from birth to adulthood, from professionals from different disciplines. This is why it is important to record information on these children from birth or diagnosis, to inform their care." Below this paragraph is another paragraph: "This database was set up by the Department of Health in 2000. The database is funded by the National Health Service through the Specialist Service Commissioners, who have responsibility for the delivery of care to children born with cleft lip and palate in England, Scotland, Wales and Northern Ireland. An independent body, the Cleft Development Group (CDG), which includes patient representative groups, clinicians and commissioners, has the overall responsibility for running the database." At the bottom of the main content area is the copyright notice: "Copyright © CRANE 2024".

Live tables

- Homepage
- Help/support
- Request an account
- System notes

1. Births by region

Number of CRANE-registered children born over the last 10 years, according to region, unit and year of birth. 

Region / Unit ▲	Year of Birth										All ▲
	2016 ▲	2017 ▲	2018 ▲	2019 ▲	2020 ▲	2021 ▲	2022 ▲	2023 ▲	2024 ▲	2025 ▲	
☐ Northern & Yorkshire	118	121	136	95	102	91	102	99	78	77	1019
└ Newcastle	59	61	53	52	47	41	54	57	37	32	493
└ Leeds	59	60	83	43	55	50	48	42	41	45	526
☐ North West & North Wales	166	129	150	133	122	107	111	97	115	133	1263
└ Liverpool	88	65	70	63	67	55	58	48	54	62	630
└ Manchester	78	64	80	70	55	52	53	49	61	71	633
☑ Trent	107	93	96	95	77	89	78	82	91	68	876
☑ West Midlands	140	135	127	93	104	92	98	78	94	76	1037
☑ East	67	75	71	67	57	47	70	59	57	60	630
☑ North Thames	135	134	125	124	112	124	112	100	114	119	1199
☑ The Spires	94	96	87	67	85	64	81	75	72	66	787
☐ South Wales & South West	86	111	97	95	97	79	79	87	95	75	901
└ Swansea	27	37	44	32	38	31	36	28	32	29	334
└ Bristol	59	74	53	63	59	48	43	59	63	46	567
☑ South Thames	123	133	110	110	115	121	90	78	109	78	1067
☑ Northern Ireland	37	40	33	34	36	30	36	34	21	33	334
☑ Scotland	70	71	61	0	1	2	62	71	56	0	394
	1143	1138	1093	913	908	846	919	860	902	785	9507

- Patient Records**
- Manage Patient Records
- Imports

- Live tables**
- 1. Births by region
- 2. Births by cleft type
- 3. Diagnosis time 2023-25
- 4. Consent 2023-25
- 5. Consent 2017-19
- 6. Outcomes 2017-19
- 7. Missing identifiers
- 8. Transfers
- 9. Imports

- Administration**
- Account Manager
- Created
- Modified



Live tables: Consent 2023-2025

Homepage

Help/support

Request an account

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Patient Records

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Live tables

1. Births by region
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Administration

Account Manager

Created

Modified

Cases by centre

Hospitals

Regions

4. Consent 2023-25

Number (%) of CRANE-registered children born 2023 to 2025, according to region / unit and consent status. (No exclusions applied). 

Region / Unit	Consent status								All
	Consent status verified				Consent status not verified				
	Consented	%	Declined	%	Awaiting verification	%	Not possible to verify	%	
<input type="checkbox"/> Northern & Yorkshire	200	78.7	23	9.1	26	10.2	5	2	254
<input checked="" type="checkbox"/> Leeds	88	68.8	11	8.6	24	18.8	5	3.9	128
<input type="checkbox"/> Newcastle	112	88.9	12	9.5	2	1.6	0	0	126
<input type="checkbox"/> North West & North Wales	329	95.4	9	2.6	4	1.2	3	0.9	345
<input type="checkbox"/> Liverpool	160	97.6	4	2.4	0	0	0	0	164
<input type="checkbox"/> Manchester	169	93.4	5	2.8	4	2.2	3	1.7	181
<input checked="" type="checkbox"/> Trent	224	92.9	2	0.8	12	5	3	1.2	241
<input checked="" type="checkbox"/> West Midlands	176	71	3	1.2	65	26.2	4	1.6	248
<input checked="" type="checkbox"/> East	152	86.4	5	2.8	19	10.8	0	0	176
<input checked="" type="checkbox"/> North Thames	309	92.8	3	0.9	20	6	1	0.3	333
<input checked="" type="checkbox"/> The Spires	178	83.6	4	1.9	31	14.6	0	0	213
<input type="checkbox"/> South Wales & South West	198	77	9	3.5	47	18.3	3	1.2	257
<input type="checkbox"/> Bristol	121	72	8	4.8	37	22	2	1.2	168
<input type="checkbox"/> Swansea	77	86.5	1	1.1	10	11.2	1	1.1	89
<input checked="" type="checkbox"/> South Thames	206	77.7	8	3	47	17.7	4	1.5	265
<input checked="" type="checkbox"/> Northern Ireland	66	75	5	5.7	16	18.2	1	1.1	88
<input checked="" type="checkbox"/> Scotland	127	100	0	0	0	0	0	0	127
	2165	85	71	2.8	287	11.3	24	0.9	2547



Live tables: Consent 2017-2019

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5. Consent 2017-19

Number (%) of CRANE-registered children born 2017 to 2019, according to region / unit and consent status. (No exclusions applied). 

Region / Unit	Consent status								All
	Consent status verified				Consent status not verified				
	Consented	%	Declined	%	Awaiting verification	%	Not possible to verify	%	
<input type="checkbox"/> Northern & Yorkshire	327	92.9	12	3.4	0	0	13	3.7	352
<input type="checkbox"/> Leeds	177	95.2	3	1.6	0	0	6	3.2	186
<input type="checkbox"/> Newcastle	150	90.4	9	5.4	0	0	7	4.2	166
<input type="checkbox"/> North West & North Wales	371	90	13	3.2	14	3.4	14	3.4	412
<input type="checkbox"/> Liverpool	180	90.9	12	6.1	1	0.5	5	2.5	198
<input type="checkbox"/> Manchester	191	89.3	1	0.5	13	6.1	9	4.2	214
<input checked="" type="checkbox"/> Trent	245	86.3	1	0.4	36	12.7	2	0.7	284
<input checked="" type="checkbox"/> West Midlands	274	77.2	15	4.2	63	17.7	3	0.8	355
<input checked="" type="checkbox"/> East	188	88.3	1	0.5	16	7.5	8	3.8	213
<input checked="" type="checkbox"/> North Thames	354	92.4	7	1.8	20	5.2	2	0.5	383
<input checked="" type="checkbox"/> The Spires	219	87.6	5	2	26	10.4	0	0	250
<input type="checkbox"/> South Wales & South West	277	91.4	3	1	11	3.6	12	4	303
<input type="checkbox"/> Bristol	172	90.5	2	1.1	9	4.7	7	3.7	190
<input type="checkbox"/> Swansea	105	92.9	1	0.9	2	1.8	5	4.4	113
<input checked="" type="checkbox"/> South Thames	312	88.4	17	4.8	8	2.3	16	4.5	353
<input checked="" type="checkbox"/> Northern Ireland	98	91.6	4	3.7	0	0	5	4.7	107
<input checked="" type="checkbox"/> Scotland	132	100	0	0	0	0	0	0	132
	2797	89	78	2.5	194	6.2	75	2.4	3144



Live tables: Outcomes 2017-2019

Help

Outcomes

Excluded from all 5-year outcomes:

1. Children who died before the age of 5 years.
2. Children with a submucous cleft palate.

Outcome specific inclusions:

5 year old index: eligible for children with a complete UCLP and complete BCLP only.

Speech: eligible for non-syndromic children with CP, UCLP and BCLP only.

Children with anomalies affecting the circulatory system or nervous system only, which do not occur as part of a syndrome, are currently included in speech reporting.

Note that Psychology data reflect children with TIM scores.

Close Print

6. Outcomes 2017-19

Number (%) of CRANE-consented children born 2017 to 2019 with reported outcomes at five years of age (excluding children who died before the age of 5 years and children with submucous cleft palate), according to region / unit. ⓘ

Region / Unit	5-year outcomes																
	Weight			Height		dmft			5 year index			Speech			Psychology		
	Eligible n	Reported n	%	Reported n	%	Eligible n	Reported n	%	Eligible n	Reported n	%	Eligible n	Reported n	%	Eligible n	Reported n	%
[-] Northern & Yorkshire	308	240	77.9	240	77.9	308	249	80.8	85	39	45.9	195	153	78.5	308	255	82.8
[-] Newcastle	144	110	76.4	110	76.4	144	120	83.3	36	24	66.7	92	75	81.5	144	126	87.5
[-] Leeds	164	130	79.3	130	79.3	164	129	78.7	49	15	30.6	103	78	75.7	164	129	78.7
[-] North West & North Wales	362	311	85.9	307	84.8	362	317	87.6	90	25	27.8	244	128	52.5	362	253	69.9
[-] Liverpool	175	141	80.6	139	79.4	175	142	81.1	44	10	22.7	119	61	51.3	175	102	58.3
[-] Manchester	187	170	90.9	168	89.8	187	175	93.6	46	15	32.6	125	67	53.6	187	151	80.7
[+] Trent	238	149	62.6	148	62.2	238	108	45.4	45	14	31.1	159	134	84.3	238	75	31.5
[+] West Midlands	268	66	24.6	66	24.6	268	108	40.3	67	1	1.5	192	83	43.2	268	126	47
[+] East	187	108	57.8	107	57.2	187	74	39.6	46	13	28.3	136	76	55.9	187	101	54
[+] North Thames	342	125	36.5	134	39.2	342	77	22.5	77	23	29.9	231	117	50.6	342	166	48.5
[+] The Spires	212	120	56.6	117	55.2	212	120	56.6	52	16	30.8	132	77	58.3	212	168	79.2
[-] South Wales & South West	272	166	61	163	59.9	272	210	77.2	55	22	40	171	108	63.2	272	216	79.4
[-] Swansea	104	90	86.5	88	84.6	104	84	80.8	25	9	36	69	40	58	104	91	87.5
[-] Bristol	168	76	45.2	75	44.6	168	126	75	30	13	43.3	102	68	66.7	168	125	74.4
[+] South Thames	307	113	36.8	111	36.2	307	199	64.8	79	32	40.5	179	131	73.2	307	167	54.4
[+] Northern Ireland	87	77	88.5	76	87.4	87	76	87.4	20	5	25	47	23	48.9	87	49	56.3
[+] Scotland	131	56	42.7	56	42.7	131	95	72.5	26	14	53.8	88	64	72.7	131	119	90.8
	2714	1531	56.4	1525	56.2	2714	1633	60.2	642	204	31.8	1774	1094	61.7	2714	1695	62.5

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Missing identifiers: Linkage and risk adjustment

7. Missing identifiers

Percentage of CRANE-consented children with missing patient identifiers on the CRANE Database, according to unit and year of birth. ⁱ

Region / Unit	Missing identifiers							
	NHS/CHI number %		Sex %		Postcode %		> 1 identifier %	
	2000-24	2025	2000-24	2025	2000-24	2025	2000-24	2025
[-] Northern & Yorkshire	0.3	0	0.2	0	0	0	0	0
[-] Leeds	0.6	0	0.3	0	0	0	0.1	0
[-] Newcastle	0	0	0	0	0	0	0	0
[-] North West & North Wales	0	0	0.2	0	0.1	0	0	0
[-] Liverpool	0	0	0.1	0	0.1	0	0	0
[-] Manchester	0.1	0	0.2	0	0.1	0	0.1	0
[+] Trent	0.4	0	1.3	0	0.2	1.6	0.2	0
[+] West Midlands	0.8	0	0.8	0	24.9	4	0.4	0
[+] East	2.5	0	0.3	0	8.1	4.5	0.3	0
[+] North Thames	1.4	0	0.7	0	2	0	0.6	0
[+] The Spires	1.1	0	0.2	2	3.8	2	0.1	0
[-] South Wales & South West	0.8	7.3	0.6	0	0.5	0	0.2	0
[-] Bristol	1.1	0	0.3	0	0.6	0	0.1	0
[-] Swansea	0.3	13	1.2	0	0.4	0	0.3	0
[+] South Thames	1.4	3.9	0.2	0	0.3	0	0.1	0
[+] Northern Ireland	2	0	0	0	0	0	0	0
[+] Scotland	0	0	0.3	0	0	0	0	0
	0.9	0.8	0.5	0.2	3.8	1	0.2	0

- Sex and postcode very important for risk adjustment
- Identifiers essential for linkage



Checking data

- Select date range
- Use advance search
 - Awaiting consent
 - Missing SMCP
 - Missing cleft type
- Use the sort function
 - Consent
 - Cleft type
 - NHS No.
 - Postcode (consented only)
 - Name (consented only)
- Export
 - Perform further checks

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Manage patients

New Record **Export Records** To start, enter some key patient details in the search bar. ⓘ

Basic **Advanced**

Administrative centre(s):

Date range: **Date of birth** to:

Consent status:

- Patient has given written confirmed consent
- Patient has declined to consent
- Consent status unknown - awaiting verification*
- Not possible to verify consent status*
- Not entered/Missing

Submucous cleft:

- Yes
- No
- Not entered/Missing

Pierre Robin:

- Yes
- No
- Not entered/Missing

Cleft type category:

- Isolated cleft lip (CL)
- Isolated cleft palate (CP)
- Unilateral cleft lip and palate (UCLP)
- Bilateral cleft lip and palate (BCLP)
- Not entered/Missing

LAHSAL code:

Search **Reset** Found: 318

Crane ...	Forenames	Surname	Date of Bir...	NHS/CHI No	Postcode	Admin No	Admin Ctr	Consent	Cleft type	LAHSAL
387			--/--/2006	943-477-4551			Salisbury	Unknown	CLAL
116			--/--/2005	943-477-3458			Guy's and St. ...	Unknown	CP	...s..
33			--/--/2004	943-477-2958			Nottingham	Unknown	CLI
122			--/--/2006	943-477-3539			Cambridge	Unable	UCLP	..HSAL
121			--/--/2006	943-477-3512			Oxford	Unable	BCLP	LAHSAL
119			--/--/2005	943-477-3482			Cambridge	Unable	
118			--/--/2005	943-477-3474			Cambridge	Unable	
114			--/--/2005	943-477-3423			Liverpool	Unable	CP	...S..
113			--/--/2005	943-477-3415			Liverpool	Unable	CP	..hs..
110			--/--/2005	943-477-3385			Cambridge	Unable	UCLP	..HS.L
108			--/--/2005	943-477-3369			Oxford	Unable	UCLP	..HSAL
107			--/--/2005	943-477-3342			Leeds	Unable	CP	..hs..
106			--/--/2005	943-477-3334			Liverpool	Unable	UCLP	..hsal
104			--/--/2005	943-477-3318			Liverpool	Unable	CP	...S..
102			--/--/2005	943-477-3288			Leeds	Unable	CP	...S..
97			--/--/2005	943-477-3229			Oxford	Unable	CP	...S..
96			--/--/2005	943-477-3202			Leeds	Unable	CP	...S..
95			--/--/2005	943-477-3199			Cambridge	Unable	
84			--/--/2005	943-477-3121			Nottingham	Unable	CP	..hs..
74			--/--/2005	943-477-3113			Oxford	Unable	CP	...S..
68			--/--/2004	943-477-3091			Oxford	Unable	CP	..HS..
67			--/--/2004	943-477-3083			Liverpool	Unable	CP	...S..
65			--/--/2004	943-477-3067			Cambridge	Unable	UCLP	32 LAHS..

Adding a new patient and updating your data

- Search
- Advanced search
- Downloading your data / Exports
- Imports
- Ideal relationship between exports and imports
 - Remember 'overwrite' of imports

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Import Templates

Please download the import template files attached below.

At birth and 1 year - import template files		5 year - import template files	
 100_growth_at_birth_g0.csv	 105_growth_at_5_years_g5.csv		
 101_growth_at_1_year_g1.csv	 305_dentistry_at_5_years_d5.csv	 310_dentistry_at_10_years_d10.csv	
 100p_psychology_at_birth_p0.csv	 405p_psychology_at_5_years_SDQTIM.csv		
	 505_speech_at_5_years_s5.csv	 510_speech_at_10_years_s10.csv	
	 205_orthodontics_at_5_years_o5.csv		

Note: Please do not alter the headings used in these files or the order of the columns in these files. Refer to the import user guide for details.

	A	B	C	D	E	F	G	H	I	J
1	form_id	crane_id	outcome_notcoll_reason_g0	clincon_nonsyndr_specify_g0	outcome_notcoll_specify_g0	gest_age	weight_g0	weight_g0_date		
2	100									
3										
4										
5										
6										
7										
8										
9										

- Available for outcomes only
- The import will replace existing entries in the data fields of the import.
- Copy the number in the first column down for each row of data you're importing.
- 1 row=1 case
- Cleft Q import will be available

Issues saving a record

396 Mouse, Mickey

Date of birth: **22/02/2016 (Age: 9 years, 11 months)**
Consent: **Patient has given written confirmed consent**
Submucous: **Not entered**
Cleft type: **Not entered**

Patient's NHS/CHI number: **Not entered**
Administrative unit name: **Cambridge**
Administrative unit number: **Not entered**
Confirmed syndromic diagnosis: **Not entered**

Consent Patient Cleft details Surgical procedures Syndromes Outcomes Notes Status

1.Cleft team details

Patient's NHS/CHI number: **2.2.02 Reason patient's NHS/CHI number not available - This is an essential field, please enter a value.**

Reason: **This is an essential field, please enter a value.**

Other reasons

Date of birth: **22/02/2016** **10**

Date deceased: **22/02/2016 (Age: 9 years, 11 months)** **10**
Only complete where applicable.

Present surname: **Mouse**
Please enter the surname the patient is currently known by.

First names: **Mickey**

Sex: Male Female
Patient gender.

Warning serious errors
Your record has serious errors and cannot be saved. Please review and fix the list below before attempting to save again.

Close

396 Mouse, Mickey

Date of birth: **22/02/2016 (Age: 9 years, 11 months)**
Consent: **Patient has given written confirmed consent**
Submucous: **Not entered**
Cleft type: **Not entered**

Patient's NHS/CHI number: **Not entered**
Administrative unit name: **Cambridge**
Administrative unit number: **Not entered**
Confirmed syndromic diagnosis: **Not entered**

Consent Patient Cleft details Surgical procedures Syndromes Outcomes Notes Status

Consent

Consent: *****
As indicated on consent form.

Patient has given written confirmed consent
 Patient has declined to consent
 Consent status unknown - awaiting verification*
 Not possible to verify consent status*

Confirm Save

This record has errors.

Save as draft Cancel

Timeliness of data entry and updates

- Transfers – pushing records to another centre
 - Allow plenty of time for new centre to invite for audit.
 - Notify new centre of transfer
- Imports – at least 1 week before deadline to allow time to address issues
- Consenting children born 2017-2019 will influence outcome eligibility numbers and data completeness.
 - Prioritise consenting now so there is time to update outcomes later.

Data entry

Any Questions



Royal College
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of England

ADVANCING SURGICAL CARE



RCS

CRANE



CLEFT REGISTRY & AUDIT NETWORK

7. Quality Improvement resources / tools

Guides

12 Guides

<https://www.crane-database.org.uk/resources/>

Resources

Filter resources

- Professional
- Public

Filter by type

- Data
- Guidance
- Guidance - Videos
- Quality Improvement
- Templates & Proformas
- Governance
- Policies
- Infographics

Submit

[Reset filter](#)

Posted 11 November 2025 in [Data](#), and [Guidance](#).

[Data Collection Milestones for 2026](#)

Posted 11 November 2025 in [Data](#), and [Guidance](#).

[Data Collection Milestones for 2025](#)

Posted 28 February 2025 in [Guidance](#).

[Guide: CRANE Account Requests and Registrations](#)

Posted 1 November 2024 in [Guidance](#), and [Governance](#).

[Information Leaflets and Parental Consent Forms](#)

Video demonstrations

6 Video demonstrations

<https://www.crane-database.org.uk/resources/>

Best browser Microsoft Edge

- Identifying records with missing registry data
- Managing patient transfers
- Recording syndromes / additional diagnoses
- Identifying missing outcome data X2
- Importing data

Resources

Filter resources

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- Public

Filter by type

- Infographics
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- Guidance - Videos
- Quality Improvement
- Templates & Proformas
- Governance
- Policies

Submit

[Reset filter](#)

Posted 12 August 2022 in [Guidance](#), and [Guidance - Videos](#).

[Video demonstration: Identifying cases missing speech data at five years of age](#)

Posted 31 March 2022 in [Guidance](#), and [Guidance - Videos](#).

[Video demonstration: Identifying cases missing psychology data at five years of age](#)

Posted 31 March 2022 in [Data](#), [Guidance](#), and [Guidance - Videos](#).

[Video demonstration: Managing Patient Transfers](#)

Supplementary tables – provided alongside the Annual Report



CLEFT REGISTRY & AUDIT NETWORK



CRANE Annual Report 2025 - Supplementary tables and information

Table of Contents (TOC)

Chapter / Section	Birth year(s)	Topic
Alerts & outliers		
Chapters 3, 4 and 5	2022-2024	Cleft service alert and outlier status 2022-2024 (NOT subject to outlier policy)
	2016-2018	Cleft service alert and outlier status 2016-2018
Registration		
2022-2024		
Chapter 3 - Section 3.1		CRANE registrations: patient and birth characteristics
		Registrations
		Sex distribution (Table 1 & 2)
		Ethnicity (Table 3)
		Cleft type distribution (Table 4)
		Robin Sequence distribution, in children with Cleft Palate (CP) only (Table 5)
		Gestational age - data completeness and gestational age
Chapter 3 - Section 3.2		Timing of diagnosis
		Timing of diagnosis - data completeness and diagnosis time in children with a cleft affecting the lip
		Timely diagnosis of cleft palate alone
Chapter 3 - Section 3.3		Referral to and contact with Cleft Services
		Referral to Cleft Services - data completeness and referral within 24 hours of birth
		Contact with Cleft Services - data completeness and contact within 24 hours of referral
Consent status		
Chapter 4	2022-2024	Consent 2022-2024
	2016-2018	Consent 2016-2018

CRANE Database 2025 Annual Report - CRANE Database

Local action plan

<https://www.crane-database.org.uk/resources/crane-local-action-plan-2024/>

To drive quality improvement

Updated to fit with local audit cycle that any member of staff or student could complete

Local Action Plan for responding to CRANE 2023 Annual Report recommendations	
The Cleft Service should complete the following details to allow for ease of review:	
Audit Title & Aim:	The Cleft Registry and Audit NETWORK (CRANE) Database. Evaluates and reports on the delivery of cleft services to children in England, Wales, Northern Ireland and Scotland with the congenital abnormality of cleft lip and/or palate.
Cleft Service / Team:	
Audit Lead:	
Action Plan Lead:	

When making your action plan, make sure to keep the objectives SMART – Specific, Measurable, Assignable, Realistic, Time-related.

Note: Data relating to each recommendation listed below can be found in the 'CRANE 2023 Annual Report' here:

<https://www.crane-database.org.uk/reports/crane-database-2023-annual-report/>

Key 1 (for the action status)
1: Awaiting plan of action
2: Action in progress
3: Action fully implemented
4: No plan to action recommendations (state reasons)
5: Other (provide information)

Key 2 (for the action priority)
HIGH: Requires urgent action, and local audit
MEDIUM: Requires prompt action, and consider local audit
LOW: Requires no immediate action or local audit

Webinars & CEN meetings 2026

We aim to hold three webinars per year

1. Making it better session (22/01/26)
2. Database Q&A session (23/02/26)
3. Database Q&A session for Clinical leads (20/05/26)

Workshop and Webinar section of our website contains summaries/slides:

<https://www.crane-database.org.uk/publications/>

CFSGBI CEN day – CRANE available to join and answer queries or present data

The screenshot shows the CRANE website interface. The top navigation bar includes 'CRANE | The Cleft Registry and Audit Network' and links for 'RESOURCES', 'REPORTS', 'PUBLICATIONS', and 'ABOUT US'. A dropdown menu under 'PUBLICATIONS' is open, showing options for 'Conferences and Meetings', 'Journals', 'Workshops and Webinars', and 'Consultation reports'. The main content area is titled 'Publications' and features a filter section on the left. The filter section has 'Filter publications' with checkboxes for 'Professional' and 'Public', and 'Filter by type' with checkboxes for 'Conferences and Meetings', 'Journals', and 'Workshops and Webinars' (which is checked). Two publication cards are displayed: one for 'CRANE 'Making it Better' learning event: January 2026' and another for 'CRANE Database Q&A Session: Summary - February 2025'.

QI resources and tools



Important: Information Governance

Please remember when contacting CRANE about a patient

- **Only use CRANE ID**
- Never send Patient Identifiable Information (PID) to our contact us page or via email:
 - Name
 - DOB
 - Hospital / NHS number



Consistent with standard IG training, and guidance by the ICO responsible for enforcing GDPR

<https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/personal-information-what-is-it/what-is-personal-data/what-is-personal-data/>



Your Questions Answered

Ad-hoc questions from attendees about any concerns or aspects of CRANE data checking and entry

Recommendations to Units based on 2025 results

- **Cleft Net East** - discuss *low CL antenatal diagnosis rates* with referring hospitals and sonography services
- **Newcastle, Spires, Trent and North Thames** - discuss their relatively *low rates of CPO diagnosis within 72hrs*. Up to 30% are being missed. Is training required?
- **West Midlands, South West, Newcastle and North Thames** – plan to improve *low rates of 24hr antenatal contact*.
- **Newcastle** - explore *low positive consent rate* relative to other regions
- **North Thames, West Midlands, Trent & Evelina London** - Action plan needed to address poor dmft data submission.
- **West Midlands and Northern Ireland** – assess and submit *sufficient number of 5-year-old Index* data to be plotted
- **Northern Ireland, West Midlands, Liverpool & North Thames** – secure psychology resource

Thank you for attending



The CRANE Database

Supporting high quality cleft care across the UK



crane@rcseng.ac.uk



<https://www.crane-database.org.uk>