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CLEFT **R**EGISTRY & **A**UDIT **N**ETWORK

CRANE – Q&A session

7 February 2024

Jibby Medina & Kate Fitzsimons

On behalf of the CRANE Database team



Royal College
of Surgeons
of England

ADVANCING SURGICAL CARE

Welcome and Introductions

No recordings please*

*For reasons associated with Information Governance and confidentiality

Any new members of staff?



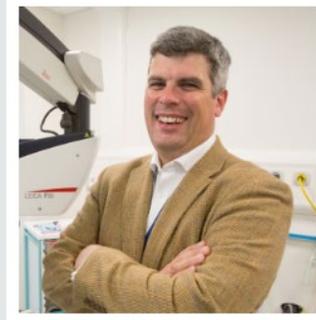
Introductions - CRANE team



CRANE



CLEFT REGISTRY & AUDIT NETWORK



Craig Russell

Clinical Project Lead

Consultant Cleft, Plastic and Reconstructive Surgeon, NHS Greater Glasgow and Clyde



Jibby Medina

Programme Manager,

Clinical Effectiveness Unit, RCS



Kate Fitzsimons

Senior Research Fellow,

Clinical Effectiveness Unit, RCS



Sophie Butterworth

Clinical Research Fellow

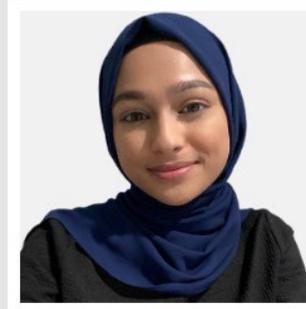


Jan van der Meulen

Methodologist,

Clinical Effectiveness Unit, RCS

Professor of Clinical



Ridwana Siddika

CEU Research Coordinator

Session aims



To answer questions about

1. Data submission deadlines
2. Data requirements
3. Data entry – including how to check and update your data
4. Quality Improvement (QI) resources / tools to support this
5. Opportunities to join future sessions

In advance of 2024 Preliminary Report submission deadline

6. Time allowing: Frequent queries received by CRANE team / helpdesk

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/>

How you can help



Consider...

- **Where CRANE team is based**
- Emails from @nhs.net addresses to an organisation outside of the NHS with @rcseng.ac.uk address
- Adding PID to a website (WordPress) hosted outside of both the NHS and the RCSEng
 - <https://www.crane-database.org.uk/contact/>
- No need to post us anything
- Telephone contact
- **Only use CRANE ID**



Source:

<https://www.clapa.com/treatment/nhs-cleft-teams/>



1. Data submission deadlines

Timeline for 2024



CRANE



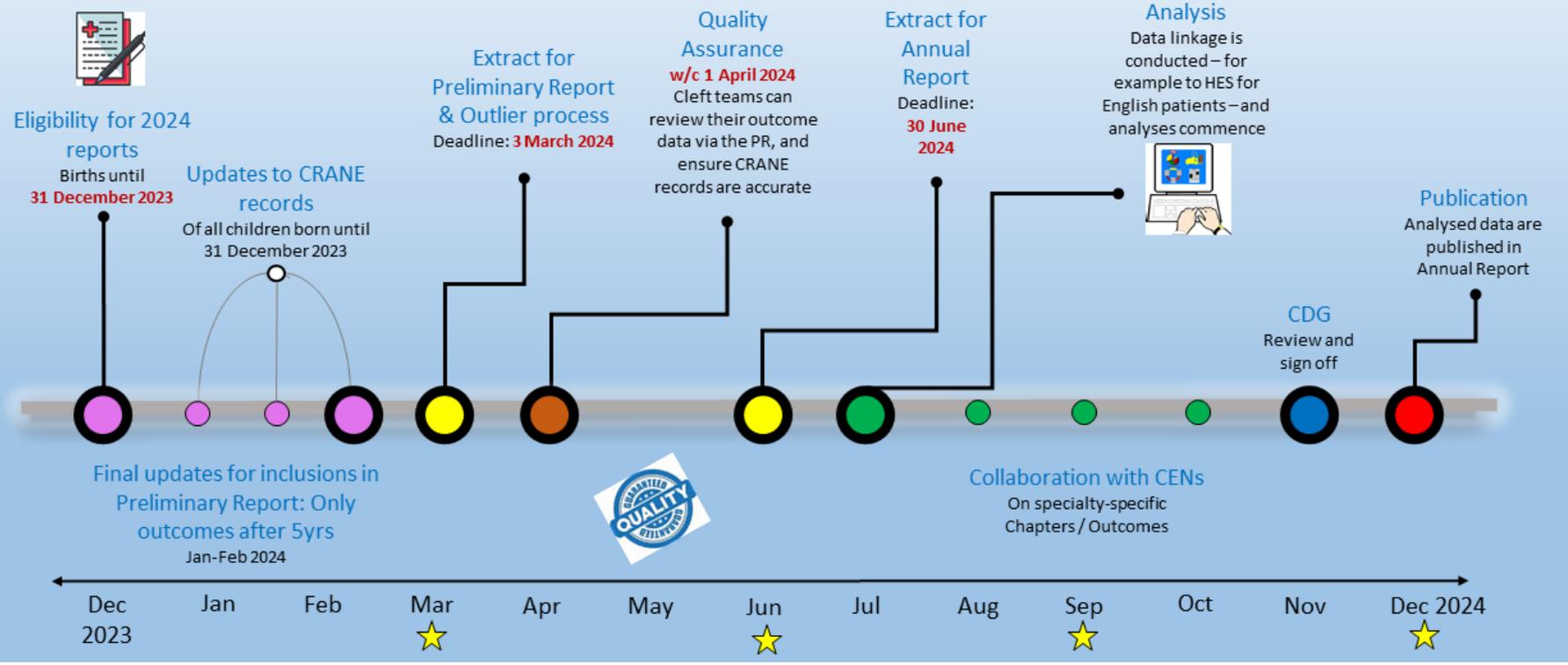
CLEFT REGISTRY & AUDIT NETWORK

Cleft Registry and Audit Network (CRANE) ANALYSIS TIMELINE 2024: Including dates for outlier process

The graphic below outlines the timeline that CRANE will work to in 2024. Key data submission deadlines are also flagged – including those for the quarterly Specialised Services Quality Dashboards. For more information on the SSQD visit <https://www.crane-database.org.uk/resources/dashboard-indicators-submitted-by-crane>. Patients recorded in CRANE up until 31 December 2023 will be included in the 2024 preliminary report – used for preliminary identification of outliers – and included in the CRANE 2024 Annual Report. Once the data for the CRANE 2023 Annual Report has been analysed, the reports will be written. The final draft then will be agreed by key stakeholders, including the CDG, before publication in December 2024.

Acronyms
 PR: Preliminary Report
 AR: Annual Report
 CDG: Cleft Development Group
 CEN: Clinical Excellence Network
 QA: Quality Assurance

Key	
Updating records	● (Pink)
Extracts	● (Yellow)
- Dashboard	★ (Yellow)
Final updates for AR	● (Brown)
Analyses for AR	● (Green)
CDG input	● (Blue)
Publication of Report	● (Red)



<https://www.crane-database.org.uk/resources/data-collection-milestones-for-2024/>

2024 data submission deadlines



CRANE deadlines:

- Sunday 3 March 2024 – Preliminary Report
 - Registrations for 2021 to 2023 births
 - 5-year outcomes for 2015 to 2017 births
- Sunday 30 June 2024 – Annual report

Dashboard deadlines:

- Friday 8 March 2024 - Q3 2023/24
- Friday 14 June 2024 – Q4 2023/24



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CLEFT REGISTRY & AUDIT NETWORK

2. Data requirements

Requirements specified in Data Dictionary & Data Collection Forms



Do you create your own?

How do you keep them aligned to regular updates?

New updates have been made to reflect:

- SMCP: Full LAHSAL code can now be entered after specifying this.
- Dental: Automatic dmft calculation.
- Psychology: TIM score scale updated & 'reason outcome not collected' for TIM added.

CRANE Data Dictionary & Data Collection Forms

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

A screenshot of a document titled 'CRANE Data Dictionary'. It contains a table with columns for 'Data Item', 'Description', and 'Data Type'. The table lists several data items such as 'Age at registration', 'Age at dental appointment', 'Age at psychology appointment', 'Administrative unit name', and 'Administrative unit code'. Each row provides a brief description of the data item and its data type (e.g., 'Text', 'Number').

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](#)

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

Updates to database / data collection



Check Data Dictionary, and CRANE data collection forms, for updates
- as data collected, and how data is collected, can change

- Quarterly Newsletter – emailed to all on contact list
- CRANE website <https://www.crane-database.org.uk/>
- X, formerly Twitter [@CRANE_News](https://twitter.com/CRANE_News)
- Particularly if you do not use CRANE data collection forms, and use locally created versions

CRANE reports



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

Cohort summary	
Data source	The CRANE Database (consented cases only). Extract taken: 4 July 2023
Birth years	Three years: 2014 to 2016
Countries	England, Wales and Northern Ireland
Inclusions	CRANE-consented children, including those without a specified cleft type
Exclusions	<ul style="list-style-type: none">• Children who died before the age of 5 years• Children with submucous cleft palate²⁸
Notes	<ul style="list-style-type: none">• Subject to outlier policy.• Data are not risk-adjusted.• Funnel plots are centred on the revised national rates after excluding data from services identified as negative outliers for consent verification (West Midlands).• Cleft Services with <10 cases are not shown on funnel plot due to insufficient data.
Raw data	'Child growth' in the supplementary tables .

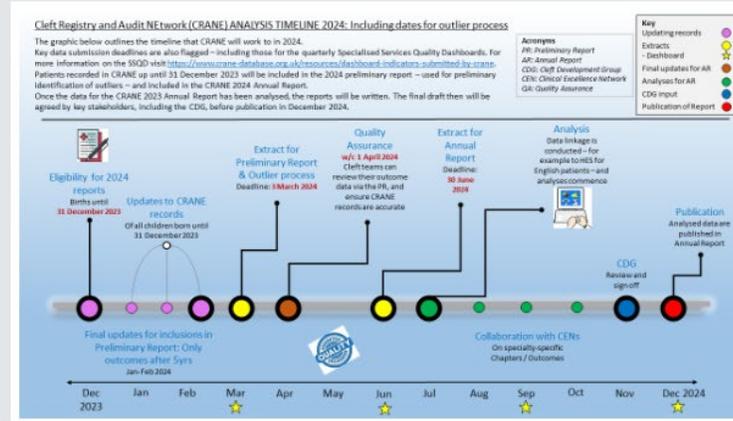
Detail on Milestones web page



Data Collection Milestones for 2024

Analysis timeline 2024: Including key data submission deadlines

Click on the image below to download your copy of the graphic representation of the CRANE Analysis Timeline 2024.



More detail about the outcomes data required can be found below.

Timeline and outcome data required for the CRANE 2024 Annual Report

- **30 June 2024:** Data collection cut off for 2024 Annual Report.
- **November 2024:** Review of report at Cleft Development Group meeting (specific date TBC).
- **December 2024:** Publication of 2024 Annual Report (specific date TBC).

We will report 5-year outcomes for patients born in 2015 to 2017 in funnel plots.

For patients whose outcome data are available and have not previously been submitted, please submit the following information required for each birth year.

Outcome \ Birth years	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
Child Growth: Height & Weight at 5 years									✓	✓	✓
Decayed, missing or filled teeth in primary dentition (dmft) at 5 years									✓	✓	✓

<https://www.cranedatabase.org.uk/resources/data-collection-milestones-for-2024/>

3. Data entry

Including how to check and
update your data

Update #1. Submucous cleft palate



Source: User feedback

- LAHSAL code now independent from SMCP box.
- Previously, LAHSAL code would change to little 's' if SMCP was ticked.
- Allows for improved accuracy of cleft type, e.g. CL+SMCP

Homepage
Request an Account
Contact Us
Patient Records
Manage patient records
Import patient records
Help
Live Tables
Administration

Edit Close Print

Is this a submucous cleft Yes No

Pierre Robin Sequence present Yes No Recording of a PR sequence being present will automatically reduce cleft description options below. Only hard palate and soft palate will be available for completion.

Forme Fruste present Yes No Presence of a "Forme Fruste" or microform cleft lip, exhibited as a depression or indentation in the lip and slight alteration of the nostril floor or alar shape. Users should record a LAHSAL code indicating an incomplete cleft of the lip on the affected side

Cleft Description

Patient's right Patient's left

Simonart's Bands - Patient's right Not present/No (.) Simonart's Bands - Patient's left Not present/No (.)

L Lip
Not present (.)
A Alveolus
Not present (.)
H Hard palate
Incomplete (I)
S

Update #2. Total dmft score



Source: Dental CEN

Total dmft score is now automatically calculated based on the individual element scores (dt+mt+ft)

This will:

- Limit data inconsistencies
- Improve the accuracy of dmft data

Outcome at 5 years (consented patients only)

1. Child Growth 2. Orthodontics **3a. Dentistry dmft** 3b. Dentistry DDE 4a. Psychology SDQ 4b. Psychology TIM 5. Speech

Paediatric dentistry: decayed, missing or filled teeth in primary dentition (dmft)

Date record taken 
dd/mm/yyyy

Total number of decayed teeth in primary dentition (dt) ⓘ

Total number of missing teeth in primary dentition (mt) ⓘ

Total number of filled teeth in primary dentition (ft) ⓘ

Total number of decayed, missing or filled teeth in primary dentition (dmft) ⓘ

Care Index ⓘ

Treatment Index ⓘ

Update #3. Psychology



Source: Psychology CEN

- TIM score scale updated to
 - Scores of 1a and 1b now collapsed to 1 (seen by psychologist but no input required)
 - scores of 2a, 2b and 2c now collapsed to 2 (psychological input provided in clinic)
- TIM score now has its own 'reason outcome not collected'
- Future related update: SDQ scores will no longer be collected for children born after 2017

The screenshot shows the 'The Cleft Registry and Audit Network' interface. The top navigation bar includes 'CRANE' and 'The Cleft Registry and Audit Network'. Below the navigation bar are buttons for 'Save', 'Cancel', and 'Print'. The main content area has tabs for 'CONSENT', 'PATIENT DETAILS', 'CLEFT DETAILS', 'SURGICAL PROCEDURES', 'SYNDROMES', 'OUTCOMES', 'NOTES', and 'HISTORY'. The 'OUTCOMES' tab is active, showing 'Outcomes' information. A yellow banner states: 'Outcome information is collected according to age of patients and cleft type: All Outcomes'. Below this, there are tabs for 'Outcome at Birth', 'Outcome at 1 year', 'Outcome at 5 years', and 'Outcome at 10 years'. The 'Outcome at 5 years (consented patients only)' section is active, showing a list of categories: '1. Child Growth', '2. Orthodontics', '3a. Dentistry dmft', '3b. Dentistry DDE', '4a. Psychology SDQ', and '4b. Psychology TIM'. The '4b. Psychology TIM' category is selected, showing the 'Tiers of Involvement Measure (TIM)' section. This section includes a date picker for 'Date of psychosocial screen using TIM at age 5' and a dropdown menu for 'TIM score'. A 'Reasons Outcomes Not Collected' dropdown menu is open, showing options: '0a. Psychologist with another patient', '0b. Psychologist on annual leave', '0c. Psychologist off sick', '0d. Psychologist not present', '0e. Psychologist declined by patient', '1. Psychological input not needed', and '2. Psychological input provided during clinic'. Below the dropdown, there are fields for 'Reason no TIM score collected', 'Clinically contraindicated (other than syndromic) reason - details', and 'Other reason - details'.

Adding a new patient and updating your data



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

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

Recap – 1 of 3



1. Use up to date Data Dictionary & Data Collection Forms
2. Search and advanced search features
3. Use Imports and Exports to update your data

4. Quality Improvement resources / tools



Guides



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

11 Guides

Resources

Filter resources

- Professional
- Public

Filter by type

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

Submit

Posted 23 September 2022 in [Guidance](#).

[Guide: Registering for an account](#)

Posted 23 September 2022 in [Guidance](#).

[Guide: Complying with the National Data Opt-out](#)

Posted 30 August 2022 in [Data](#), [Guidance](#), and [Templates & Proformas](#).

[Guide: Psychology outcomes data entry](#)

Video demonstrations



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

6 Video demonstrations

Best browser Microsoft Edge

- Managing patient transfers
- Recording syndromes and additional diagnoses
- Importing data
- Identifying missing outcome data X2
- Finding patients without verified consent

Resources

Filter resources

- Professional
- Public

Filter by type

- Infographics
- Data
- Guidance
- 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](#)



Checking data completeness and accuracy



- Demo

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

- Live Tables (Reports) – behind log-in

Table 3. Diagnosis time

Number (%) of CRANE-registered children born between 2000-2021, and in 2022 alone, with a cleft lip and/or palate according to the timing of diagnosis and cleft type. ¹

Year / Cleft type	Time of diagnosis in relation to birth - n (%)														All
	Antenatal		At birth		Within 72 hours		≤1 week		≤1 month		≤6 months		>6 months		
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	
▼ 2000-2021	7,095	43.2	6,789	41.4	377	2.3	868	5.3	425	2.6	489	3.0	372	2.3	16,415
CL	2,438	63.5	1,173	30.6	26	0.7	71	1.8	23	0.6	78	2.0	29	0.8	3,838
CP	154	2.3	4,506	66.6	322	4.8	753	11.1	369	5.5	356	5.3	307	4.5	6,767
UCLP	3,039	81.8	621	16.7	4	0.1	19	0.5	5	0.1	26	0.7	3	0.1	3,717
BCLP	1,356	82.0	280	16.9	3	0.2	3	0.2	2	0.1	7	0.4	2	0.1	1,653
Non specified	108	24.5	209	47.5	22	5.0	22	5.0	26	5.9	22	5.0	31	7.0	440
▼ 2022	360	44.8	324	40.3	49	6.1	26	3.2	26	3.2	14	1.7	5	0.6	804
CL	143	69.8	56	27.3	4	2.0	-	-	-	-	1	0.5	1	0.5	205
CP	3	1.0	208	68.2	38	12.5	22	7.2	23	7.5	8	2.6	3	1.0	305
UCLP	134	85.4	22	14.0	-	-	1	0.6	-	-	-	-	-	-	157
BCLP	63	91.3	6	8.7	-	-	-	-	-	-	-	-	-	-	69
Non specified	17	25.0	32	47.1	7	10.3	3	4.4	3	4.4	5	7.4	1	1.5	68
	7,455	43.3	7,113	41.3	426	2.5	894	5.2	451	2.6	503	2.9	377	2.2	17,219

NOTE: Totals for timing of diagnosis by year(s) are presented along the top row for each grouping of years and overall total (gray lines).



Supplementary tables – provided alongside the Annual & Prelim Report



Preliminary report

CRANE Audit Report 2023 - Supplementary tables and information

Table Of Contents (TOC)

Chapter / Section	Birth year(s)	Topic
Registration	2020-2022	
Chapter 3 - Section 3.1		CRANE registrations: patient and birth characteristics Registrations Patient characteristics Gestational age Birth weight
Chapter 3 - Section 3.2		Timing of diagnosis Timing of diagnosis for all cleft types Timely diagnosis of cleft palate
Chapter 3 - Section 3.3		Referral to and contact with Cleft Services Referral and contact time
Alerts & outliers	2014-2016	
Chapters 4 and 5		Cleft service alert and outlier status
Consent status	2020-2022 Registrations 2014-2016 Outcomes	
Chapter 4		Consent
Audit Outcomes at 5 years of age	2014-2016	
Chapter 5 - Section 5.1		Child growth Child growth - data completeness and BMI
Chapter 5 - Section 5.2		Dental health Dental health - data completeness, dmft, treatment and care index



CRANE Preliminary Report 2023 - Supplementary tables

Table Of Contents (TOC)

Content	Birth year(s)	Topic	Inclusion/Exclusion criteria
Consent verification	2020-2022 2014-2016	Consent verification for all cleft teams.	Excluded submucous cleft palates and those dying before 5y from denominators.
Cleft types	2020-2022 2014-2016	Cleft type distribution for all cleft teams.	Consented cases only, excluding submucous cleft palates and those dying before 5y.
PBS	2014-2016	Pierre Robin Sequence.	Consented CP cases only, excluding submucous cleft palates and those dying before 5y.
Syndromes	2014-2016	Information on the recording of syndromic cases.	Consented cases only, excluding submucous cleft palates and those dying before 5y.
Child Growth	2014-2016	Child growth data completeness at 5 years of age.	Consented cases only, excluding submucous cleft palates and those dying before 5y.
Body Mass Index (BMI)	2014-2016	Child growth at 5 years of age, for only children with both height and weight recorded.	Consented cases only, excluding submucous cleft palates and those dying before 5y.
Dental Health 5yrs	2014-2016	Dental health at 5, as measured by decayed missing and filled teeth (dmft) scores.	Consented cases only, excluding submucous cleft palates and those dying before 5y.
Dental Health 10yrs	2014-2016	Dental health at 10, as measured by DMFT - data completeness only.	Consented cases only, excluding submucous cleft palates and those dying before 10y.
Facial Growth data	2014-2016	Facial growth data completeness of Five Year Old Index scores.	Consented complete UCLP cases only, excluding submucous cleft palates and those dying before 5y.
Facial Growth 5yr Index	2014-2016	Facial growth, as measured by Five Year Old Index scores.	Consented complete UCLP cases only, excluding submucous cleft palates and those dying before 5y.
Speech completeness	2014-2016	Speech data completeness at 5 years of age, as measured by the Cleft Audit Protocol for Speech - Augmented (CAPS-A) scores.	Consented CP, UCLP & BCLP cases only, excluding submucous cleft palates, those dying before 5y, and those with diagnosed syndromes recorded on CRANE.

Local action plan



<https://www.crane-database.org.uk/resources/crane-local-action-plan-2023/>

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



Data Check Workbooks – Feb 2024



On Friday 2nd Feb, a CRANE extract was taken to identify cases with:

1. Missing/incomplete LAHSAL codes
2. LAHSAL codes considered clinically implausible (could be issue with 's' & 'S' looking the same when handwritten).

L	A	H	S	A	L
l	a	h	s	a	l

3. Unverified CRANE consent < 2016 births (before we introduced health/education consent)
4. Unverified CRANE consent, health linkage or education linkage for births ≥ 2016
5. Missing NHS/CHI number
6. Missing postcode



Data Check Workbooks – Feb 2024



- Each cleft service will receive one 'DATA checks' workbook with several tabs
- Each tab will have several columns:
 - Cleft service
 - Year of birth (ordered chronologically from 2000)
 - CRANE ID
 - Data issue e.g. lahsal code with issue
- Recommendations for services with lots of cases to update/correct:
 - Consent & LAHSAL code: prioritise 2015-2017 & then 2021-2023 births for 2024 reporting.
 - NHS number & postcode: prioritise recent 10-year birth cohort to support linkage.



Recap – 2 of 3



Please make use of

1. Guides and Video demonstrations
2. Live Tables (Reports) – behind log-in. E.g. Missing identifiers
3. Supplementary materials incl. Tables and Local Action Plan
4. Data checks workbooks – sent out 3 years running



Recap – 3 of 3



Please make use of

- “Search” CRANE website – distinct from CRANE Database access
 - <https://www.crane-database.org.uk/>
- X, formerly Twitter [@CRANE News](https://twitter.com/CRANE_News)
- Newsletters
- Annual Reports
- Helpdesk crane@rcseng.ac.uk
- **Please remember to only use CRANE ID when contacting us about your data**



5. Opportunities to join future sessions

Stakeholder engagement for 2023/24



Check out the Workshop and Webinar section of our website <https://www.crane-database.org.uk/publications/> for summaries of all past sessions.

We aim to hold four webinars per year

1. Annual Report presentation and review
2. Database Q&A session – Winter (prior to preliminary report deadline)
3. Preliminary Report presentation and review
4. Database Q&A session – Spring (prior to annual report deadline)

6. Frequent queries received by CRANE team / helpdesk

Q1. Who can update data?



- CRANE does not mandate who does this
- When data entered for a patient – option to look back at other data fields to check completion and accuracy
 - Particularly for cleft type and syndromes

Sections of Database we suggest all feel responsible for



Registry details

- Registration
- Sex and **cleft type**
- Timing of diagnosis
- Contact with team
- Robin sequence
- **Syndrome**
- Gestational age
- Birth weight

Consent

- **Verification**

Blue items affect data completion for all

Outcome data

Age 1

- Growth
- Psychology – 1st screen

Age 5

- Growth
- Dental
- Facial growth
- Speech
- Psychology

Q2. Patient transfers



- Some concerns from CEN groups about patients from other services being included in outcome reporting
- For managing transfers use the relevant guides and video demonstrations
 - Video <https://www.crane-database.org.uk/resources/video-demonstration-managing-patient-transfers/>
 - Guide <https://www.crane-database.org.uk/resources/guide-quick-reference-for-managing-patient-records/>
- Please consider your colleagues at other services – last minute ‘pushes’ to be avoided. Pulls in are ok.

Q4. Reason outcome not collected



- Patient has emigrated
- Patient has moved out of area and no forwarding address

Reasons Outcomes not collected

Reason outcome not collected

```
outcome_notcoll_reason (_g0, _p0,  
_g1, _g5, _o5, _d5, _p5, _s5, s_10,  
d_10)
```

- 1= Patient deceased or emigrated
- 2= Patient transferred in or out of area
- 3= Syndromic Diagnosis
- 4= Clinically contraindicated (other than syndromic) - this record type for this patient
- 5= Lack of staff / facilities / equipment
- 6= Patient DNA / cancelled / did not consent / cooperate
- 9= Other reason

Q5. FAQs



CRANE



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E.g. Registrations: Births in UK

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

15. Should families not based in England, Wales and Northern Ireland be included/excluded from being registered on the CRANE Database?

Patients who are not resident in England, Wales and Northern Ireland, should not be registered in the CRANE Database.

Specifically, the following children **should not** be registered in the CRANE Database, nor have outcome data collected in CRANE:

- Babies from parents not based in the UK, born with a cleft in a UK hospital who then returned to their home country. This is because CRANE is a registry for babies from families residing in England, Wales and Northern Ireland.
- Babies born outside of the UK with a cleft and who travel to the UK to receive cleft care services, from either the NHS or private cleft care providers, then return to their home country after their cleft care. Recording of this information would distort the estimation of incidence of cleft and evaluation of cleft care services in England, Wales and Northern Ireland.

Note: Where we have made reference to the United Kingdom (UK), in the text above for simplicity, we are referring to England, Wales and Northern Ireland. As these are the countries currently submitting data to the CRANE Database.

The current guidance by the Cleft Development Group is that patients from abroad are not registered in CRANE. Their treatment pathway started elsewhere and have not been accessing our health care system from birth. This is particularly important in the context of evaluating the burden on cleft team services.

Your Questions Answered

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

Thank you

Join our next webinar in May - Preliminary report review

 [@CRANE News](#)

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

 crane@rcseng.ac.uk