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## CRANE 2023 – February Q&A session



28 Feb 2023

J Medina

On behalf of the CRANE Database team



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# Welcome and Introductions

No recordings please\*

\*For reasons associated with Information Governance and confidentiality

# Aims – answer questions about



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1. Data requirements
2. Data entry – including how to check and update your data
3. Quality Improvement (QI) resources / tools to support this

In advance of 2023 reports' submission deadlines

4. Opportunity to understand which resources most known and found useful

# Which CRANE resources do you use?



- CRANE website – distinct from CRANE Database access
  - <https://www.crane-database.org.uk/>
- Twitter [@CRANE News](https://twitter.com/CRANE_News)
- Newsletter
- Annual report
- Helpdesk [crane@rcseng.ac.uk](mailto:crane@rcseng.ac.uk)
- Others



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# Data requirements

# Timeline for 2023



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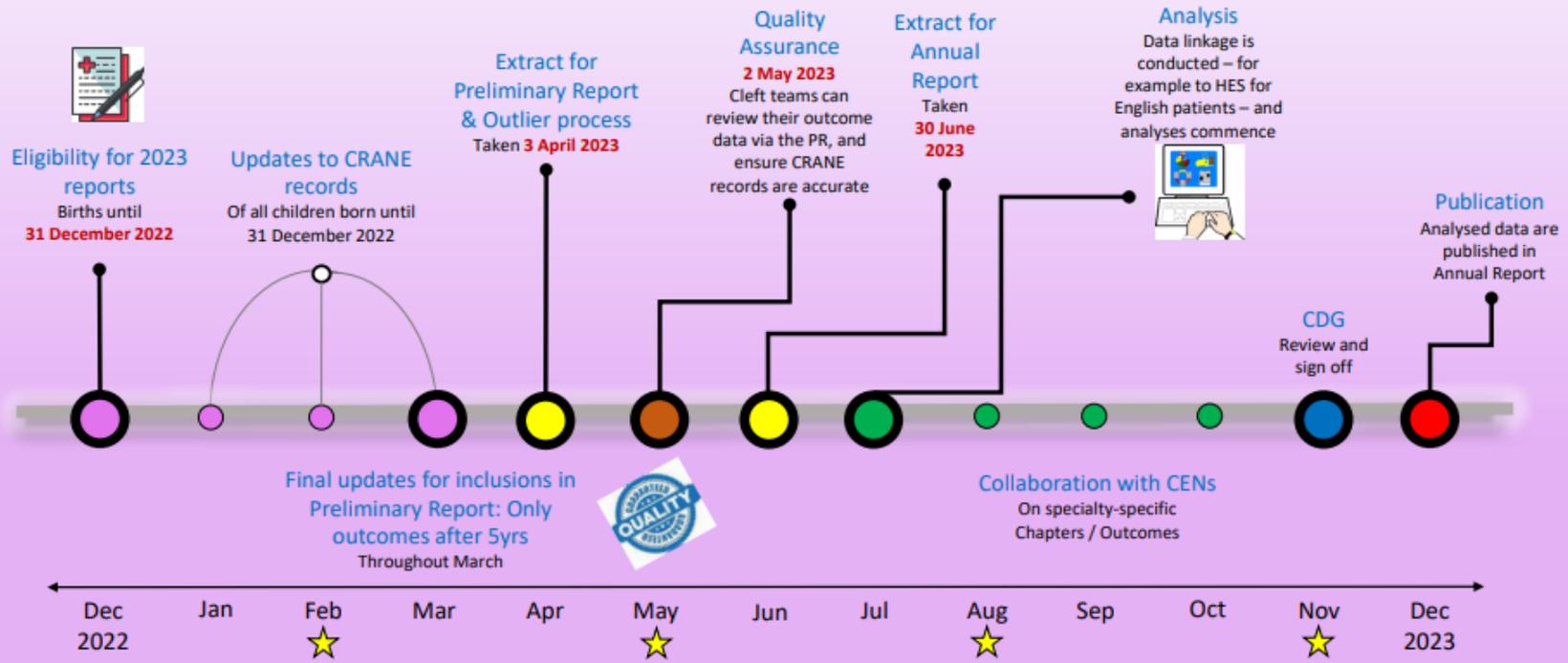
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## Cleft Registry and Audit Network (CRANE) ANALYSIS TIMELINE 2023: Including dates for outlier process

The graphic below outlines the timeline that CRANE will work in 2023. 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 2022 will be included in the 2023 preliminary report – used for preliminary identification of outliers – and included in the CRANE 2023 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 2023.

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

Key	
Updating records	🟪
Extracts - Dashboard	🟡
Final updates for AR	★
Analyses for AR	🟠
CDG input	🟢
Publication of Report	🔴



<https://www.crane-database.org.uk/resources/data-collection-milestones-for-2023/>

# CRANE Annual Report 2023



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- Data entered by Friday 30 June 2023 included
- 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)
	Birth years	Three years: 2012 to 2014. Plus summary information on 2015 births <sup>30</sup>
	Denominator	1,285 Children with a recorded height and weight at 5 years
	Numerator	Number of children in each body mass index (BMI) category (underweight, healthy weight, overweight and obese)
	Exclusions	<ul style="list-style-type: none"><li>• Children without consent to data collection</li><li>• Children who died before the age of 5 years</li><li>• Children with submucous cleft palates<sup>31</sup></li><li>• Children without recorded height and weight at the age of 5</li></ul>

<https://www.crane-database.org.uk/reports/crane-database-2022-annual-report/>

# Supplementary tables

## - new layout for 2022



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of Surgeons  
of England  
ADVANCING SURGICAL CARE

### CRANE Audit Report 2022 - Supplementary tables and information

#### Table Of Contents (TOC)

Chapter	Birth year(s)	Topic
Registration	2018-20 combined and 2021	
Chapter 3.1		Registrations in CRANE
		<a href="#">3.1.1. Registrations</a>
		<a href="#">3.1.3. Sex and Cleft type</a>
Chapter 3.2		Timing of diagnosis
		<a href="#">3.2.2. Timing of diagnosis for all cleft types</a>
		<a href="#">3.2.3. Timing of diagnosis for clefts involving the lip</a>
Chapter 3.3		Timely diagnosis of cleft palate
		<a href="#">3.3. Timely diagnosis of cleft palate</a>
Chapter 3.4		Gestational age and birth weight
		<a href="#">3.4.2. Gestational age</a>
		<a href="#">3.4.4. Birth weight</a>
Chapter 3.5		Contact with cleft services
		<a href="#">3.5.2. Referral time and contact time</a>
Consent status	2012-14 combined and 2015	
Chapter 4.1		<a href="#">4.1. Consent</a>

Provided in a workbook alongside the Annual Report

<https://www.crane-database.org.uk/reports/crane-database-2022-annual-report/>



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# Data entry



# Future update: Developmental Defects of Enamel (DDE)



- Guides
- Data collection forms and data dictionary
- Exports and Imports
- All soon to be updated:  
Normal SN = score of 1

Learning  
from  
Psychology

Paediatric dentistry: Developmental Defects of Enamel (DDE)

Please select one of the options below for each dental region: ⓘ

	SN (Right)	URB	URA	ULA	ULB	SN (Left)
Normal	<input type="radio"/>					
Hypomineralisation	<input type="radio"/>					
Hypoplasia	<input type="radio"/>					
Abnormal shape/size	<input type="radio"/>					
Congenitally missing	<input type="radio"/>					
Unable - restored	<input type="radio"/>					
Unable - carious	<input type="radio"/>					
Unable - extracted	<input type="radio"/>					
Unable - exfoliated	<input type="radio"/>					
Not present	<input type="radio"/>					
DDE Score subtotals	<input type="text"/>					
Total 5 year DDE score						
Date record taken						

- Preliminary information on completeness – April 2023

## 2. Adding a new patient and updating their data



- Demo

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

- Search

- Imports

- Reports – Tables 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.

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).

# 3. Checking data completeness and accuracy



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- Demo

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

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

# 4. 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](#)

# 5. Video demonstrations



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

## 6 Video demonstrations

### 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](#)

# 6. FAQs. E.g. Registrations: Births in UK



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## 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.

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



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# Quality Improvement resources / tools

# 1. Recap



1. Data Dictionary & Data Collection Forms
2. Search and advanced search
3. Imports and Exports
4. Reports behind log-in e.g. Missing identifiers
5. Guides and video demonstrations

## 2. Workbooks, March 2022



- Try to complete workbooks shared with services March 2022
- These contained missing or potentially incorrect data flagged within our system
- Correcting these errors will improve the accuracy of the data used for future analyses and reporting

# 3. Local action plan



<https://www.crane-database.org.uk/resources/crane-local-action-plan-2022/>

To drive quality Improvement

Note:

Recs 9, 4 & 11, 26 & 27

Cleft Team Local Action Plan for responding to CRANE 2022 Annual Report Recommendations	
The cleft team 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 and Northern Ireland with the congenital abnormality of cleft lip and/or palate.
Cleft care 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 2022 Annual Report' here:  
<https://www.crane-database.org.uk/reports/crane-database-2022-annual-report/>

Key 1 (for the action status)	Key 2 (for the action priority)
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)	<b>HIGH:</b> requires urgent action, and local audit <b>MEDIUM:</b> requires prompt action, and consider local audit <b>LOW:</b> requires no immediate action or local audit

**Please note: The recommendations listed below are those for action by cleft services.**



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# Frequent queries received by CRANE helpdesk

# Which sections of the Database do you 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 – 1<sup>st</sup> screen

### Age 5

- Growth
- Dental
- Facial growth
- Speech
- Psychology

# 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

# 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/>

# Q3. Warning about consent to linkage to health and education data blocking saving of outcome data



70 records missing consent to link to health data and education data (out of 23,608)

WARNING: Please select the Linkage of CRANE data to health data field  
WARNING: Please select the Linkage of CRANE data to education data field

Information and other warnings

CONSENT PATIENT DETAILS CLEFT DETAILS SURGICAL PROCEDURES SYNDROMES OUTCOMES NOTES HISTORY

Consent

Consent status ⓘ

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

\* Please give further details ⓘ

Linkage of CRANE data to health data ⓘ

- Patient has given written confirmed consent
- Patient has declined to consent
- Consent status unknown - awaiting verification\*
- Not possible to verify consent status\*
- Registered prior to new 2016 system

Linkage of CRANE data to education data ⓘ

- Patient has given written confirmed consent
- Patient has declined to consent
- Consent status unknown - awaiting verification\*
- Not possible to verify consent status\*
- Registered prior to new 2016 system

# Q4. Data submission deadlines



- Monday 3 April 2023 – extract for Preliminary report
- Friday 30 June 2023 – extract for Annual report
  - 5-year outcomes for 2014 to 2016 births
  - Registrations for 2020 to 2022 births
- Use our resources to check your data
- Contact [crane@rcseng.ac.uk](mailto:crane@rcseng.ac.uk) with queries



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# Your Questions Answered

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

# New starters



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## Training resources

- Colleagues who have attended this session
- Guides and videos
- Search function
- Encourage colleagues to scroll down
- Newsletters +
- Tues 23 May next proposed Q&A



# Resources helpful to support data entry and checking?



**DATA COLLECTION FORM 1:  
PATIENT REGISTRATION, CLEFT DETAILS, SYNDROMES, AND OUTCOMES AT BIRTH & 1 YEAR**

This form is provided as a template to aid CRANE data collection. The data recorded on this form **MUST** be transferred to the CRANE electronic database. Paper forms cannot be accepted for entry.

The criteria for adding a new registration to the CRANE Database are:

- Cleft patient (or suspected cleft until confirmed).
- Documented consent for full registration – otherwise notification data<sup>Δ</sup> only.
- Patient/parents are UK residents/nationals.
- NHS and Private Patients included.

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**1. Patient Registration** Note: This section is used to collect basic patient information for cleft patients. It is required for each new patient.

**1.1. Patient consent**

<p><sup>Δ</sup><b>Consent status</b></p> <p><input type="checkbox"/> Patient has given written confirmed consent</p> <p><input type="checkbox"/> Patient has declined to consent</p> <p><input type="checkbox"/> Consent status unknown - awaiting verification*</p> <p><input type="checkbox"/> Not possible to verify consent status*</p>	<p><sup>Δ</sup><b>Linkage of CRANE database to Health data</b></p> <p><input type="checkbox"/> Patient has given written confirmed consent</p> <p><input type="checkbox"/> Patient has declined to consent</p> <p><input type="checkbox"/> Consent status unknown - awaiting verification*</p> <p><input type="checkbox"/> Not possible to verify consent status*</p>
<p>*Please give further details _____</p>	<p><sup>Δ</sup><b>Linkage of CRANE data to Education data</b></p> <p><input type="checkbox"/> Patient has given written confirmed consent</p> <p><input type="checkbox"/> Patient has declined to consent</p> <p><input type="checkbox"/> Consent status unknown - awaiting verification*</p> <p><input type="checkbox"/> Not possible to verify consent status*</p>



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# Thank you



[crane@rcseng.ac.uk](mailto:crane@rcseng.ac.uk)



[@CRANE News](https://twitter.com/CRANE_News)



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

