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CLEFT REGISTRY & AUDIT NETWORK

CRANE 2023 – May Q&A session

23 May 2023

S Butterworth and J Medina

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?



Aims – answer questions about



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 Annual Report submission deadline

Key CRANE resources



- 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
- Others



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Data requirements

Timeline for 2023



CRANE



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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 to 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.

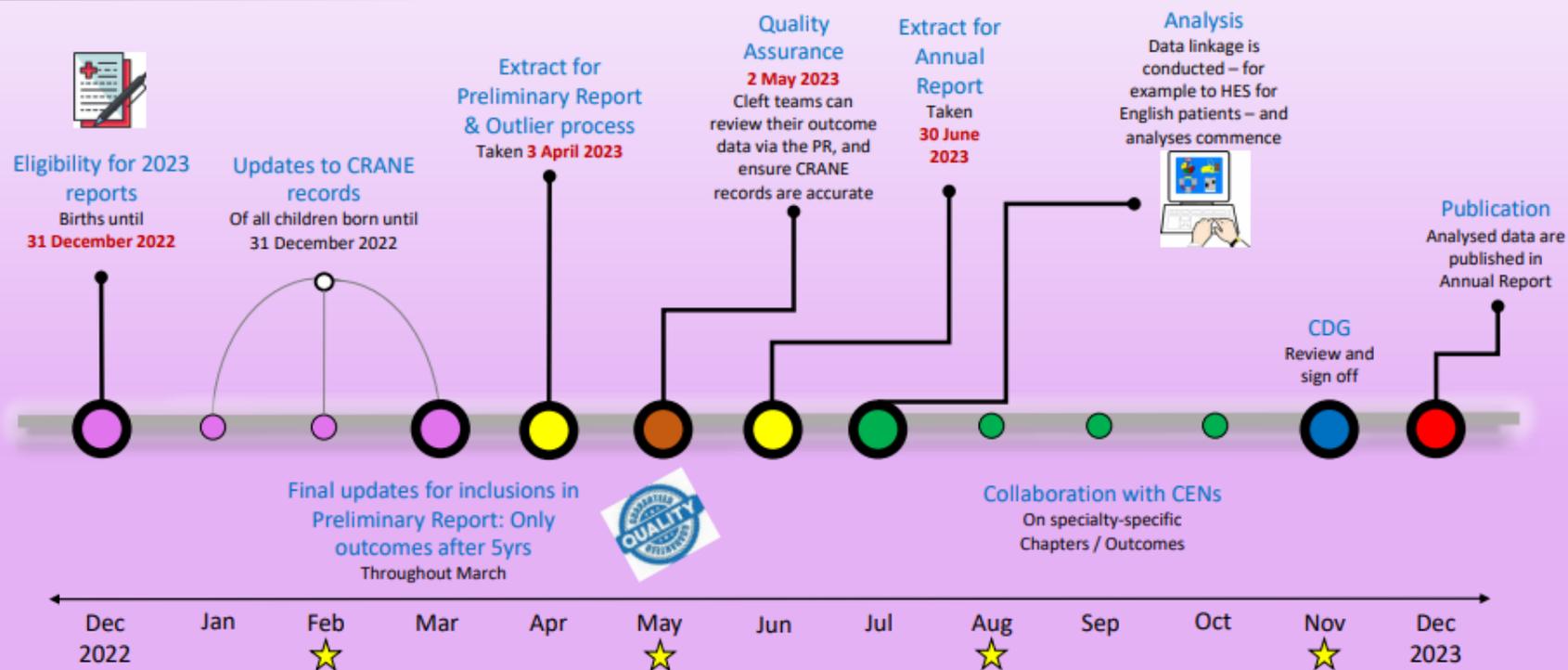
Once the data for the CRANE 2023 Annual Report has been analysed, the reports will be written. The final draft then will be agreed by key stakeholders, including the CDG, before publication in December 2023.

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



- 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 ³⁰
	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">• Children without consent to data collection• Children who died before the age of 5 years• Children with submucous cleft palates³¹• Children without recorded height and weight at the age of 5

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

Supplementary tables – provided alongside the Annual & Prelim Report



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 3.1.1. Registrations 3.1.3. Sex and Cleft type
Chapter 3.2		Timing of diagnosis 3.2.2. Timing of diagnosis for all cleft types 3.2.3. Timing of diagnosis for clefts involving the lip
Chapter 3.3		Timely diagnosis of cleft palate 3.3. Timely diagnosis of cleft palate
Chapter 3.4		Gestational age and birth weight 3.4.2. Gestational age 3.4.4. Birth weight
Chapter 3.5		Contact with cleft services 3.5.2. Referral time and contact time
Consent status	2012-14 combined and 2015	
Chapter 4.1		4.1. Consent



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 type	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.

Preliminary report



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Data entry

1. 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 Scottish CHI number

CRANE Data Dictionary & Data Collection Forms

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

A thumbnail image of the CRANE Data Dictionary document, showing a table with columns for 'Variable Name', 'Description', and 'Data Type'. The table lists various variables such as 'Age at registration', 'Gender', 'Ethnicity', 'Dental Health Outcome', and 'Developmental Defects of Enamel (DDE)'. The document is titled 'CRANE Data Dictionary' and includes a table of contents.

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/>

Recent update: Developmental Defects of Enamel (DDE)



- Update: Normal SN = score of 1
- Guides
- Data collection forms & data dictionary
- Exports and Imports
- Preliminary information on completeness – Dental CEN

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	●	●	●	●	●	●
Hypomineralisation	●	●	●	●	●	●
Hypoplasia	●	●	●	●	●	●
Abnormal shape/size	●	●	●	●	●	●
Congenitally missing	●	●	●	●	●	●
Unable - restored	●	●	●	●	●	●
Unable - carious	●	●	●	●	●	●
Unable - extracted	●	●	●	●	●	●
Unable - exfoliated	●	●	●	●	●	●
Not present	●	●	●	●	●	●
DDE Score subtotals						
Total 5 year DDE score						
Date record taken						

2. Adding a new patient and updating their data



- Demo

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

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

3. Checking data completeness and accuracy



- Demo

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

- Live Tables (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. 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).

5. Video demonstrations



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

6 Video demonstrations

- Managing patient transfers
- Recording syndromes and additional diagnoses
- Importing data
- Identifying missing outcome data
- 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](#)

4. Guides



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

11 Guides

Resources

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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](#)

6. FAQs. 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.

Quality Improvement resources / tools

1. Recap



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

2. Data Check Workbooks - 2023



- Each cleft service will receive one 'DATA checks' workbook with several tabs:
 - 1. NHS number, 2. Postcode, 3. LAHSAL codes, 4. dmft, 5. Miscellaneous
 - Workbooks were also sent last year but some services reported missing these.
 - For services with a lot of missing data (e.g. postcode), we suggest focusing on the current annual report birth years (e.g. 2014-16 for 2023 AR).

Frequent queries received by CRANE 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.

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. 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. Data submission deadlines



- E.g. 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 with queries

Timeline for 2024 has been published



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.

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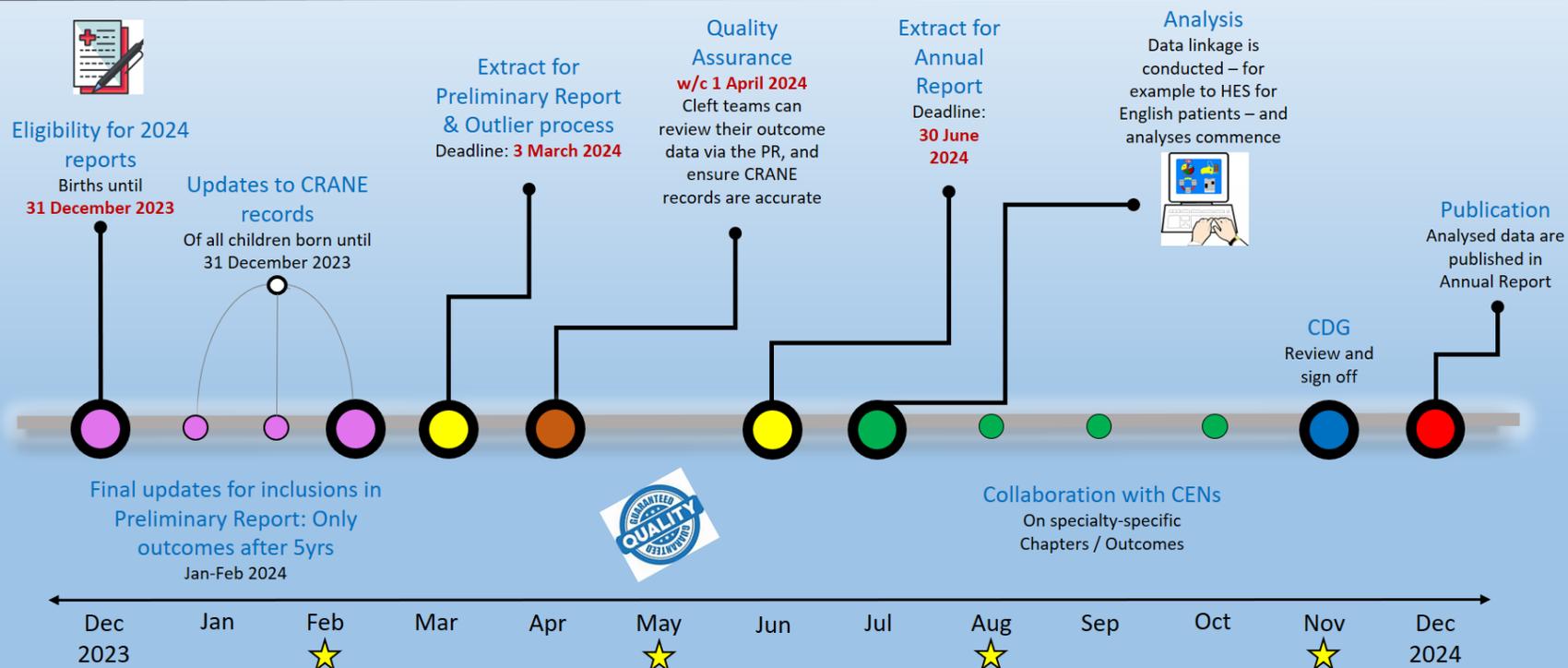
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- CDG input ●
- Publication of Report ●



Stakeholder engagement for 2024



- Making it better (January)
- Database Q&A sessions (February & May)
- Preliminary report presentation and review (May)

Your Questions Answered

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

New starters



Training resources

- Colleagues who have attended this session
- Guides and videos
- Search function
- Encourage colleagues to scroll down
- Consider staffing of CRANE helpdesk
- Consider transfers

- Newsletters +
- Next Q&As in early 2024 – we will try to change the day of the week



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 ^Δ only.
- Patient/parents are UK residents/nationals.
- NHS and Private Patients included.

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>^ΔConsent status</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>^ΔLinkage of CRANE database to Health data</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>^ΔLinkage of CRANE data to Education data</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

Stay in touch and contact us if you need further support



[@CRANE News](#)



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



crane@rcseng.ac.uk