



CRANE Database

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CRANE Database Meeting: Question and Answer (Q&A) Session

7 February 2024

1. Background

Q&A sessions are held twice yearly to provide cleft services with direct access to our project team, who can answer questions about data collected in CRANE. The aim of these sessions is to improve the quality of the data captured within the database. The timing of these sessions fit with key [data submission deadlines](#) for the year and allow cleft services to raise any issues identified by the application of the [Outlier Policy](#)¹. The Outlier process identifies cleft services as positive or negative outliers in relation to consent verification, data completeness, and process and outcome indicators. It allows teams to reflect on the data captured by all cleft services and suggests ways to improve the quality of the data that we present to our key stakeholders.

This Q&A session was open to all cleft service team members involved in the submission of data to the CRANE Database for yearly CRANE reporting and for quarterly [SSQ Dashboard submissions](#).

This document provides a summary of the key points and queries raised at the Q&A session.

1.1. Attendees

The meeting was facilitated by Jibby Medina (JM), Programme Manager for CRANE, and Dr Kate Fitzsimons, Senior Research Fellow for CRANE. It was attended by a total of 26 representatives from different specialties within almost all regional cleft services (see **Table 1**), as well as 3 CRANE team members.

Table 1. Number of attendees by cleft service

Cleft Services – in England, Wales, Northern Ireland and Scotland	Number of attendees
Newcastle	1
Leeds	2
Belfast	3
Manchester	1
Cambridge	1
GOSH	2
Scotland	1
Swansea	1
Bristol	1
Nottingham	1
Unknown (MS Teams failed to record identity)	12
CRANE Project Team	3
Total	29

¹ Approved by the [Cleft Development Group](#) 1 April 2021.

1.2. Aim

The overall aim was to provide CRANE Database users with an opportunity to ask the CRANE team questions in advance of the 2024 Preliminary Report submission deadline.

See slides presented at Q&A session – published alongside this document – for further information on the points below.

1.3. Important: Information Governance

- CRANE is an organisation outside of the NHS.
- When contacting CRANE about a patient, please **only use CRANE ID**.
- Never send Patient Identifiable Information (PID) to CRANE via email or our 'contact us' webpage. PID includes: **Name, DOB, Hospital / NHS number**.
- There is no need to post anything.
- Telephone contact is always available, if necessary.

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/>

2. Data submission deadlines – Overview of key dates for 2024 and the data required

2.1. Data deadlines and birth years

- Signpost to the [CRANE Database Timeline for 2024](#) for all key dates.
 - A note below the timeline and outcome data required for the CRANE 2024 Annual Report information was queried by a meeting attendee. The note appeared to suggest that only DMFT at 10 years needed submitting for the preliminary report. This is not the case.
 - **Correction actioned:** The note has now been revised to reflect that DMFT data at 10 years is the only data submitted which is only shown in Preliminary Reports at this time. I.e. "This information has yet to be published in Annual Reports. Nevertheless, this data should be submitted to inform summary information provided in the Preliminary Report to cleft services and Clinical Excellence Networks (CENs) in April 2024. The Dental CEN will provide guidance on appropriateness of inclusion of DDE at 5 years and DDE & DMFT at 10 years in future Annual Reports."
- 3 March 2024 deadline for data entry for preliminary report.
 - Registrations for 2021 to 2023 births.
 - 5-year outcomes for 2015 to 2017 births.
- 30 June 2024 deadline for data entry for Annual Report.

2.2. Dashboard deadlines

- Confirmed dates: 8 March 2024 – Q3 2023/24, and 14 June 2024 – Q4 2023/24.

3. Data requirements

3.1. CRANE Data Dictionary and data collection forms

- The [CRANE Data Dictionary](#) is updated regularly and provides information about what is collected. The **Data Collection Forms** (accessed via the same link) are also updated and new updates have been made to reflect recent changes to the CRANE Database (see 4.1 to 4.3 below).
- If you use your own data collection forms, please ensure that these are also updated regularly to ensure data items are not missing.

3.2. Updates to database / data collection

- Check Data Dictionary and CRANE data collection forms for updates. Updates will be shared via:
 - Quarterly Newsletter – emailed to all on contact list.

- CRANE website <https://www.crane-database.org.uk/>
- X, formerly Twitter [@CRANE_News](#)

3.3. CRANE reports

- Tables / Figures presented are calculated using valid data as denominators.
 - Subject to the usual inclusions and exclusions. These are specified in the 'Cohort summary' at the beginning of each section in the Annual Report. For the most recent example, see <https://www.crane-database.org.uk/reports/crane-database-2023-annual-report/>

3.4. Milestones web page

This contains further information on the particular birth cohorts included in the upcoming reports <https://www.crane-database.org.uk/resources/data-collection-milestones-for-2024/>

4. Data Entry – Database updates & how to check and update your data.

4.1. Update #1: Submucous cleft palate

- A full LAHSAL code can now be entered after specifying the presence of a submucous cleft palate (SMCP). Ticking the SMCP box previously placed a little 's' in the LAHSAL code data field on CRANE, limiting the cleft type to cleft palate only.
- This database change will improve cleft type accuracy, e.g. for those with cleft lip and SMCP.
- See FAQs #13 and #14 on our [FAQs for professional's webpage](#) for more information on SMCP and atypical facial cleft.

4.2. Update #2: Total dmft score

- Total dmft score is now automatically calculated based on the individual element scores (dt+mt+ft).
- This change should limit data inconsistencies and improve the accuracy of dmft data.

4.3. Update #3: Psychology

- The TIM score scale has been updated:
 - Scores of 1a and 1b now collapsed to 1.
 - Scores of 2a, 2b and 2c now collapsed to 2.
- A 'reason outcome not collected' for TIM scores has also been introduced separately, as requested by the Psychology CEN.
- the SDQ scores for children born after 31 December 2017 will no longer be collected, as requested by the Psychology CEN.
- A meeting attendee asked about data being submitted for children younger than age 5 and after their 6th birthday. The age of assessment is included in the Annual Report Supplementary Workbook. Upon review during the meeting, it became evident that there was an error in the table – in relation to the Psychology at 5 years data. **Correction actioned:** This error has been corrected and an updated version of the Supplementary workbook is available on our website.

4.4. Adding a new patient and updating your data

- Guidance for adding a new patient and updating your data can be found on the CRANE Website. The database has various functions to support this:
 - Search/Advanced search.
 - Downloading your data / Exports.
 - Imports. – consider the relationship between exports and imports. Remember that imports 'overwrite' data in the Database so we suggest that you export first, check / amend, then import, so as not to lose existing data.

5. Quality improvement (QI) resources and tools – key resources and tools to support this

5.1. Guides

- There are [11 guides](#) posted on the CRANE website under resources, ranging from how to register for an account to complying with the National Data Opt-out and outcome data entry.
- Please check the guides before contacting us as many issues can be resolved by reading these or watching our videos.

5.2. Video demonstrations

- There are [6 Video Demonstrations](#) posted on the CRANE website under 'resources' taking you step-by-step through guidance on:
 - Managing patient transfers – a meeting attendee flagged wanting to understand more about volumes of cases transferred across services. Action: More information on transfers will be provided at the next Q&A session in May 2024.
 - Recording syndromes and additional diagnoses.
 - Importing data.
 - Identifying missing outcome data (X2).
 - Finding patients without verified consent.
- We encourage you to use this as a first resource.

5.3. Checking data completeness and accuracy

- Live demonstration of tables – total of 8 tables.
- For those with access to the database you can check data in the live reporting tables.
- Some of the tables are being updated in 2024 to show the three-year birth cohort included in the annual report for that year. This will provide a valuable check.
- Supplementary tables are provided alongside the Preliminary and Annual Reports.
 - They contain the summary data that feeds into the reports and they also highlight if a particular Trust is an outlier.
- Local action plan is updated to fit with a local audit cycle that any member of staff or student could complete.
 - The template is available on our website and includes examples of data completeness, process (e.g. contact within 24hrs of referral) and outcome indicators with suggested actions to improve data completion.
- Data Check Workbooks – Feb 2024.
 - On Friday 2nd Feb, a CRANE extract was taken to identify cases with:
 - Missing/incomplete LAHSAL codes.
 - LAHSAL codes considered clinically implausible (could be issue with 's' & 'S' looking the same when handwritten). This is really important for future risk assessment.
 - Unverified consent < 2016 births (before we introduced separate health/education consent).
 - Unverified consent status for CRANE, health linkage or education linkage for births ≥ 2016.
 - Missing NHS/CHI number.
 - Missing postcode.
 - Consider including capital and small letters to document LAHSAL code on your paper forms.
 - By the end of this week you will receive the data check workbooks with several tabs.
 - Recommendations for services with lots of cases to update / correct were given in the presentation and included in email.

6. Opportunities to join future sessions

- 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 – this took place 22 January 2024.
2. Database Q&A session – Winter (prior to preliminary report deadline) – on 7 February 2024 (today).
3. Preliminary Report presentation and review – date to be circulated/proposed 15 May 2024.
4. Database Q&A session – Spring (prior to annual report deadline) – date to be circulated/proposed 24 May 2024.

7. Q&A session

- Ad-hoc questions from attendees were discussed – responses and actions by the CRANE project team have been documented throughout this summary.
- The registration of submucous cleft palate cases was discussed. Several concerns were raised:
 - The inconsistency between teams in registering SMCP cases,
 - The impact this inconsistency may have on reported rates, e.g timely diagnosis,
 - The challenge in knowing what LAHSAL code to now enter for these cases,
 - Whether patients with a bifid uvula only should be registered, and
 - Whether children with SMCP who are asymptomatic and subsequently discharged from the cleft service should be removed from the database.
- The CRANE Project Team reassured attendees that SMCP cases are now excluded from between-centre comparisons in timely diagnosis rates. It was acknowledged that more guidance on these cases is required to ensure a more consistent approach between services. We are hopeful that this topic will be added to the agenda of the next CDG meeting. **Action:** We intend to update our FAQs after the CDG meeting. In the meantime, we encourage you to register SMCP cases.
- A summary of frequent queries received by the CRANE team / helpdesk were also discussed and are included in the slides published alongside this document.

8. Recap of resources available to new starters

- Colleagues who have attended this session,
- On the website:
 - Guides and videos – links listed in section 5 of this document.
 - Use up-to-date Data Dictionary & Data Collection Forms.
 - Annual Reports.
 - Supplementary materials incl. Tables and Local Action Plan.
 - Search function on the website – box top-right <https://www.crane-database.org.uk/>
 - Encourage colleagues to scroll down – when viewing CRANE web pages (lots of information added).
- In the Database / behind the "CRANE Data Entry System" log-in:
 - Search and advanced search features.
 - Use Exports and Imports to update your data.
 - Live tables.
- Newsletters + emails to your inbox or found in News section of the website.
- X, formerly known as Twitter.
- HelpDesk – crane@rcseng.ac.uk.

Thank you to all attendees for their contribution to this session.

Join us on 24 May 2025 – 10:30 to 12:00 for the next 'CRANE Data Q&A' in advance of the deadline to extract the data for the Annual Report – suitable for anyone who records, checks and submits data. A Microsoft Teams / Outlook invitation will be sent to all CRANE contacts at least 6-weeks prior to this event.

You are welcome to ask further questions or provide feedback via crane@rcseng.ac.uk, the [contact us](#) page of the website or at [@CRANE News](#).