



CRANE Database

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

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1. Background

Q&A sessions are to be held twice yearly to provide cleft services with direct access to the CRANE project team. The aim is to answer questions about data requirements and improve the quality of the data captured within the database, meet key [data submission deadlines](#) for the year and address issues identified by the application of the [Outlier Policy](#)¹. The Outlier Policy identifies cleft services as positive or negative outliers in relation to consent verification, data completeness, and process and outcome indicators, allowing teams to reflect on the data captured by all cleft services and improve the reliability of the outcomes that we as a community are able to present for all 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 CRANE², and was attended by a total of 40 people: 39 representatives from different specialties within almost all regional cleft services (see [Table 1](#)) and 1 CRANE team member.

Table 1. Number of attendees by cleft service

| Cleft Services – in England, Wales and Northern Ireland | Number of attendees |
|---|---------------------|
| Newcastle | 1 |
| Leeds | 1 |
| Liverpool | 3 |
| Manchester | 5 |
| Trent | 3 |
| West Midlands | - |
| Cleft Net East | 2 |
| North Thames | 4 |
| The Spires | 3 (Oxford) |
| South Wales | 4 |
| South West | 3 |
| Evelina London | 2 |
| Northern Ireland | 4 |
| Scotland | 4 |
| CRANE Project Team | 1 |
| Total | 40 |

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

² Part of the CRANE team since January 2014, and responsible for the redevelopment of the Database in 2015-16.

1.2. Aims & objectives

Provide CRANE Database users with an opportunity to ask the CRANE team questions about:

- data requirements,
- data entry – including demonstrations of how to check the accuracy and completeness of current data and update it, and
- quality improvement (QI) resources/tools to support this.

Address ad-hoc questions about any concerns or aspects of CRANE data checking and entry.

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

2. Data requirements – Overview of key dates for 2023 and the data required

2.1. Data deadlines and birth years

- Signpost to the [CRANE Database Timeline for 2023](#) for all key dates.
- 2 April 2023 deadline for data entry for preliminary report (extract taken Monday 3 April).
- 30 June 2023 deadline for data entry for Annual Report (note: extract taken following Monday).

2.2. Birth years for 2023 annual report

- Registry data 2020-2022 (3 years)
- Outcome data 2014-2016 (3 years)

3. Data entry – including how to check and update your data

3.1. CRANE Data Dictionary and Data Collection Forms

- The [CRANE Data Dictionary](#) provides information about what's collected, and the **Data Collection Forms** (accessed via the same link) are kept updated as new data items are added.
- Please scroll down on the above page to access the two data collection forms.
- If you use your own data collection forms please ensure that these are updated regularly e.g. check syndrome status and developmental defects of enamel have been added.

3.2. Adding a new patient and updating their data (including imports and downloading your data to check data completeness and accuracy)

- Live demonstration of how to add a new patient.
- Live demonstration of report tables accessible behind the log-in.
- Live demonstration of data export and import using search and advanced search function.
- The [11 'how-to' guides](#) and [6 video demonstrations](#) were flagged as useful resources for understanding how to use the CRANE Database.
- Only children born in and resident in the UK should be recorded in CRANE. See [FAQs #11–15 on our website](#) for more detail.

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

4.1. CRANE Data Dictionary and Data Collection Forms

- The [CRANE Data Dictionary](#) provides information about what's collected, and the **Data Collection Forms** (accessed via the same link) are kept updated as new data items are added.

4.2. Workbooks – March 2022

- Completing and returning the data workbooks circulated in March 2022 highlighting missing or potentially incorrect data flagged in our system will help improve the accuracy of the data used for future analyses.
- The [Local Action Plan](#), produced each year alongside the Annual Report, contains ideas for local QI initiatives.

5. Helpdesk Q&As – frequent queries received

1. Who can update data?
 - CRANE does not mandate who does this
 - When entering data, do look back and check completion of other data fields – particularly consent, cleft type, syndromic status
2. How do we transfer a patient?
 - 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/>
3. I am unable to save outcome data?
 - Ensure all data items on consent tab are completed, including consent to linkage to health and education data (see page 1 of the [Data Dictionary](#)), even if the current status is 'Unknown, awaiting verification'.
4. When are the next data submission deadlines?
 - Please check the [data collection milestones](#) each year.

6. Question and Answer session

Ad-hoc questions from attendees were discussed and live demonstrations conducted where possible. A summary of the questions asked have been collated below:

Question 1: Cleft type is appearing as “not entered” followed by the cleft type – I have tried re-entering but this hasn’t solved the problem?

Answer: The most common reason for this is that the Simonart's Bands data item (at the top of the 'cleft description' screen) is 'missing'. The Simonart's Band data needs to be completed – set to 'not present' or 'yes' – to generate the cleft type. All elements of the cleft description need to be completed (8 data items – listed on page 4 of the [Data Dictionary](#)) – otherwise incorrect or missing cleft type will limit data items available for completion.

Question 2: Do you suggest the data collection forms are printed off for each child and where would they stay if so?

Answer: If you are unable to enter data for a child directly in a clinic setting then we would recommend taking a printed version instead to the clinic setting. This could be completed as the child is seeing the different specialists and at the end of the clinic this should then be given to the data coordinator (or equivalent) to enter onto the CRANE Database. The paper copy can either be kept in the patient’s medical record if you still use paper or scanned into the patient’s electronic record.

Question 3: I don't import the forms, I directly enter the data to the patient's records by editing it. Do I need to import it for data entry?

Answer: Import is a tool to help with a mass upload if this is more convenient for a team. It is not mandatory but was brought in during the 2016 redevelopment to address a senior management request for interoperability.

Question 4: We have a small number of children who are showing as 'consent unknown, awaiting verification'. Do we need to chase verification from these families as we cannot access their profiles to add in any data/exclusions etc...?

Answer: If consent status is unknown then it suggests that this family has not yet been approached to get consent. We would recommend approaching the family for consent which can be face-to-face or by phone/email. The following FAQ's – [FAQ#8 and FAQ#9](#) – on our website provide additional information on obtaining consent.

Question 5: What about patients who have been chased for many years and have not given a decision about consent?

Answer: If consent status remains unknown despite chasing the family to get consent, and a range of methods to obtain consent have been employed (face-to-face/by phone/email), then these records would stay as 'consent unknown, awaiting verification'. If the patient does attend a clinic in the future then they could be approached for a 'yes' or 'no' at this time.

Question 6: For patients who are no longer under our care how do we remove them?

Answer: We do not like to remove patient from the CRANE Database. The normal pathway is to transfer the patient to the new unit they are moving to. This could be done at the same time as the transfer letter to the new unit is sent. If you have not been made aware of the transfer then a 'reason outcomes not collected' should be recorded for these cases in the outcome sections of the database e.g. Option 2 = Patient transferred in or out of area (see options listed on page 6 of the [Data Dictionary](#)). You could also provide CRANE with a list of CRANE IDs and we can see if they have been registered at another site.

7. Recap of resources available to new starters

- Colleagues who have attended this session
- Guides and videos – links listed in section 3.2 of this document
- 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)
- Newsletters + emailed to your inbox or found in [News](#) section of the website

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

Join us on 23 May 2023, 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](#).