



CRANE Database

Tel: 020 7869 6610

E: crane@rcseng.ac.uk

W: www.crane-database.org.uk

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

23 May 2023

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 Sophie Butterworth (SB), CRANE Clinical Fellow, and Jibby Medina (JM), Programme Manager for CRANE, and was attended by a total of 30 people: 27 representatives from different specialties within almost all regional cleft services (see **Table 1**) and 3 CRANE team members.

Table 1. Number of attendees by cleft service

Cleft Services	Number of attendees
Newcastle	1
Leeds	1
Liverpool	-
Manchester	1
Trent	-
West Midlands	-
Cleft Net East	5
North Thames	5
The Spires	3 (Oxford and Salisbury)
South Wales	2
South West	3
Evelina London	1
Northern Ireland	3
Scotland ²	2
CRANE Project Team	3
Total	30

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

² As of 1 January 2023, cleft services across Scotland have joined teams in England, Wales and Northern Ireland in recording their data in the CRANE Database. Read more about this [here](#).

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 enter new data, 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.
- 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)

Subject to the usual inclusions and exclusions: Refer to Summary tables in previous Annual Reports.

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

3.1. CRANE Data Dictionary and Data Collection Forms

- The [CRANE Data Dictionary](#) provides information about what is 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.
- New updates have been completed to reflect Scottish CHI number as well as NHS Number.
- Developmental Defects of Enamel (DDE) – collection commenced in May 2022 (with an update in March 2023)³ summary information on DDE data will be shared with the dental CEN, and will not be a part of the annual report until agreed with the dental CEN that sufficient data completeness criteria has been met.

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.
- Be careful to not “overwrite” data recorded in the CRANE Database when Importing data. One way to check this is to export your data first, then check and update it before adding to the import template.

³ <https://www.crane-database.org.uk/resources/guide-dental-outcomes-data-entry/>

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 is collected, and the **Data Collection Forms** (accessed via the same link) are kept updated as new data items are added.
- Live tables are available only with login. It is useful for searching information by categories, such as region or diagnosis time.

4.2. Workbooks – May 2023

- Advised participants to check and update their data, informed by the workbooks circulated in May 2023, where possible. These highlight missing or potentially incorrect data flagged in our system. Although it is not mandatory to complete the workbook, it will help improve the accuracy of the data used for future analyses and can allow us to link to other datasets.
- The [Local Action Plan](#), produced each year alongside the Annual Report, contains ideas for local QI initiatives.

5. Helpdesk Q&A's – 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. What should we do if a patient cannot be traced?
 - If you can no longer contact a child e.g. the child has emigrated or transferred to an unknown cleft service and you are unable to complete the outcome data fields for that child, please select a 'reason outcome not collected' (see page 6 of the [Data Dictionary](#)).
5. When are the next data submission deadlines?
 - Please check the [data collection milestones](#) each year.
 - Please consider your colleagues at the other services – last minute “pushes” to be avoided, especially on the deadline day. Pulls in are ok.

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: Can syndrome status be changed?

Answer: Yes, syndrome status can be changed at any time. Use the search facility to find the person in question, click on “edit” to update their record. The syndrome tab along the tab can be selected and new details can be added.

Question 2: Can you search for data when you have a viewer status?

Answer: Yes, you can search data for your cleft service, but you cannot change it. If you need to change any data, someone else with 'editor' status will have to do it for you. If you are having any trouble searching and checking your data after reviewing our resources please contact the CRANE team for support.

Question 3: What is the function of import 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. If you prefer you can enter data directly to each patients' individual record.

Question 4: Should children with a submucous cleft palate (SMCP) be registered on CRANE?

Answer: Guidance for children born with SMCP can be found in [FAQ #11](#) and #12. Children with a submucous cleft palate are excluded from outcome reporting in the CRANE Annual Report. It may be appropriate to discuss this matter further with the Cleft Development Group as some members present were concerned that children born with SMCP were skewing their delayed detection of cleft palate figures.

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: If a new-born baby with cleft dies before being referred to or seen by the cleft service: should we register the child on CRANE?

Answer: CRANE is a national registry and therefore a child who is born alive but subsequently dies should be registered. This information can be gathered from the hospital at birth rather than contact with the family at a difficult time. Coding will exclude the children who died before the age of 5 from outcome reporting.

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 + emails to your inbox or found in [News](#) section of the website

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

Join us in 2024 for the next 'CRANE Data Q&A' in advance of the deadline 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](#).