



CRANE Database

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CRANE Database: Key Stakeholder Engagement with Clinical Excellence Networks (CENs)

October 2022 – April 2023

1. Background

In 2022, the CRANE Database project team developed their communications strategy to improve engagement with our key stakeholders including NHS Trusts, cleft services (made up of representatives from the CEN's) and service users.

1.1. Aims & objectives

1. Communicate with clinicians to help them use the outputs of CRANE to improve patient care – by providing comparative information on procedures and outcomes following cleft lip and/or palate repair.
2. Raise awareness of the work of CRANE – to increase levels of participation among cleft services, and enhance the case ascertainment and data completion. This will be achieved by:
 - Promoting the CRANE project – marking its key milestones (incl. deadlines to upload data to the quarterly dashboard) and generally raising awareness of this quality improvement programme.
 - Communicating directly with cleft services to facilitate participation and data completion.
 - Encouraging the use of the CRANE's products (reports, resources, etc.), such as helping sites/staff make best possible use of outputs/products/reports.
 - Providing stakeholders with an opportunity to share views and discuss challenges and barriers to data submission.

Implementing this strategy included: (a) Approaching the Chair of each CEN group for an invitation to provide a CRANE update at their meetings; and (b) ensuring a member of the CRANE project attended, on behalf of the team, to provide the update and engage with stakeholders.

These meetings, were key stakeholder engagement opportunities, and were open to all cleft service members attending their respective CEN group meetings.

This document provides a summary of the key points raised at those meetings.

1.2. Attendees

The meetings were organised with the Chair of each CEN group and facilitated by Sophie Butterworth (SB) from the CRANE project team. They were attended by varying numbers of representatives from each specialty group with representation from all regional cleft services (see **Table 1**).

Table 1. Number of attendees for each CEN group

CEN group	Number of attendees
Specialist nurses	34
Psychologists	24
Orthodontists	20
Surgeons	29
Paediatric dentists	10
Speech and language therapists	43
ENT/Audiologists	7
Total	167

The following topics were discussed at the meetings:

- Use of CRANE resources
- Person/s responsible for CRANE data entry at cleft services
- Data fields attendees felt responsible for
- Barriers to collection or recording of data

Suggested and planned actions are highlighted through this summary.

2. Use of CRANE resources

The section below summarises the discussion regarding which CRANE resources were used by CEN members.

2.1. CRANE Website

- 51/167 (31%) reported that they had used the Website (<https://www.crane-database.org.uk/>).
- Some stated this was to access to the database itself, for obtaining leaflets for families, and to view annual reports.
- Speech CEN felt that it would be useful to have more resources on CFSGBI website – links to particular pages such as the Annual report or infographic. CRANE will ensure that there are clear links from the CFSGBI website to key CRANE resources.

2.2. Twitter

- 12/167 (7%) reported that they used / followed CRANE on “X”, formerly known as Twitter ([@CRANE_News](https://twitter.com/CRANE_News)).
- Those doing so did so in own time, as hospital Trusts in general do not allow access to social media.

2.3. Newsletter

- 57/167 (34%) reported that they received / read the quarterly Newsletters circulated via the audit inbox (and published online at <https://www.crane-database.org.uk/news/>).
- Stakeholder feedback indicated hyperlinks would be useful on the Newsletter. SB response provided: Working hyperlinks are available if the attachment (in emails circulated) is opened. The email contains an image (a preview) but not all stakeholders realised this of read the top line of text asking users to open the attachment.
- **ACTION:** The CRANE project team will explore the feasibility of adding hyperlinks to body of the Newsletter email to make accesses easier; and remove the image of the Newsletter if causing confusion.

2.4. Annual Report

Two main groups within this discussion, those who read the full report and those who just review a section of the report that they feel is most relevant to them.

- Approximately 1/3 read full report.
- Approximately 2/3 read a selection or the chapter relation to their particular specialty.
- Some found the AR too detailed and would prefer a simplified CEN specific summary.
- **ACTION:** The CRANE project team will explore the feasibility of producing a shorter/more condensed annual report or refine the specialty specific report chapters to ensure they are more easily accessible.

2.5. Helpdesk

- Several members within each CEN group utilised the helpdesk – contacting the CRANE team at crane@rcseng.ac.uk

OVERALL ACTION: The CRANE project team will create a one page list of key resources, for the benefit of CENS. Included in this document as **Appendix 1**. For each CEN lead to distribute to ensure that any new members receive this and can be added to the CRANE contact list if they wish.

3. Who enters data onto CRANE?

CEN group members were asked if they entered data directly onto the CRANE Database themselves or if a data coordinator or member of the administration team completed this on their behalf.

3.1. Designated data coordinator

- Everyone attending had a person within their team/cleft service responsible for data entry.
- For the majority present they completed a data entry form – often bespoke for that service or for each discipline and passed this to a data coordinator to enter onto the database. SB took this opportunity to flag the ‘CRANE data collection forms’ published alongside the CRANE Data Dictionary – reviewed yearly and kept updated online after every update to data collection (<https://www.crane-database.org.uk/resources/crane-data-dictionary/>).

3.2. Other member of the team/cleft service

- A few members of the nursing and SLT CEN groups entered data directly without using a data coordinator.
- Multiple members of the psychology CEN also entered data directly.
 - This CEN reported frequent changeover of staff in data entry role as often an assistant psychologist (filling 1-year posts) entering the data.
 - Previous discussion at ‘Making it better’ session highlighted that new/junior staff, in short-term roles, do not always benefit from appropriate handover/training for accurate data entry; which can lead to errors in the data.

SUGGESTED ACTIONS – for Cleft Services:

- Having a central data coordinator, who is familiar with entering data onto the database, has been shown to improve the accuracy of services data. Where feasible, this approach has proved beneficial.
- Using the data collection forms provided by CRANE could reduce likelihood of error.

4. Which data fields do you feel responsible for?

- All CEN groups felt a responsibility to approach families for consent.
- **Registration data:** Often collected early on by members of the nursing CEN. Nurses reported sometimes feeling uncomfortable asking for ethnicity data from families and keen to have further education particularly for new members of staff on recording of LAHSAL code. Nurses also record data for several other standards that are not collected by (or reported on) by CRANE.
- SUGGESTED ACTION – for Cleft Services: Consider using the CRANE data collection forms (published on the website) and asking parents if they can tick which ethnic group their child belongs to.
- **Child growth data:** Collected in the main by the nursing CEN staff but several services do not have a nurse present at the audit clinics. In this situation another member of the team was able to record height and weight or for some services this was not possible to obtain.
- SUGGESTED ACTION – for Cleft Services: For services that do not have a specialist nurse available for audit clinics to agree another member of the cleft service who could take height and weight measurements. Missing data for this field is currently restricting further analysis. CRANE will also look at feasibility of linking to national height and weight data taken at age 5.

- **Dental data:** Collected by the dental CEN staff although due to hub and spoke services the results were not always fed back to the central team effectively.
- **Facial growth data:** Collected by the orthodontic CEN staff although due to hub and spoke services the results were not always fed back to the central team effectively. The Orthodontic CEN do not feel facial growth is a reflection of their work and would consider other measures such as PAR score or psychological outcomes to be more relevant. They plan to discuss at a joint meeting with the Surgical CEN in the near future.
- **SUGGESTED ACTION – for Cleft Services:** For services with a hub and spoke model of care to ensure that staff at spoke services have the same equipment available to record dental and facial growth data as the hub service and a way of feeding this information back to a named person within the cleft service.
- **Speech data:** Collected by the speech and language therapy CEN staff. Trained CAPS-A listeners were not available at all services therefore some services had to outsource this to other services.
- **Psychology data:** Collected by the psychology CEN staff.
- **ENT/Audiology data:** Yet to agree on outcomes and begin data collection.
- **Cleft surgeons:** Felt an oversight of all areas of the report was important.

5. Barriers to collection or recording of data

CEN groups were encouraged to think about barriers to collecting or recording data. The responses have been grouped into the main themes:

- **COVID**
 - COVID causing difficulties with data collection or clinic organisation.
 - The backlog of children needing to be seen post-COVID had yet to be resolved.
- **Data entry difficulties**
 - Competence in using published guidance and Microsoft Excel.
 - Some felt getting the data not an issue as such but rather getting it onto the database could be.
 - Some had difficulties due to entering incorrect data, due to lack of understanding of clinical scoring system – this was only identified when services were noticed to be an outlier in the preliminary or annual report.
 - Recording data in several places can be an extra burden.
 - **ACTION:** The CRANE project team will, subject to staffing availability, seek to provide: Two Question & Answer (Q&A) specific webinars and two webinars relating to the preliminary and annual report – each year, to support users with queries. Including matters to do with data entry/upload. Questions can also be asked throughout the year, and in advance of these sessions via crane@rcseng.ac.uk.
- **Staff**
 - Staff turnover high in some areas.
 - Lack of admin staff to support data entry.
 - Maternity leave of some staff members meant gaps in data as roles were not filled.
 - Not enough trained/calibrated dental staff to attend every clinic therefore patients missed.
 - Not all SLTs trained to be CAPS-A listeners.
- **Clinic Set-up**
 - Some only had audit clinics for patients with particular cleft types (complete UCLP and BCLP).
 - Some services seeing large numbers virtually still and therefore struggling with data completeness.

- Limited availability of clinic slots.
- Challenges prioritising audit as a clinical visit.
- Limited clinical resources in some clinic settings.
- Reliance on coordinators booking patients in at the right age/time point.
- **Patients that do not attend (DNA)**
- **Lack of consent**
 - Some children had data collected locally but services did not realise that they had no consent for outcome collection on CRANE and that these could therefore not be added.
 - Regional differences – one service reported multiple parents not keen to consent.

Next CEN meetings will be held in late 2023 / early 2024.

Subject to CRANE project team staffing availability, the Chair of each CEN group will be approached as done so in 2022/23 for an invitation to provide a CRANE update at these meetings.

Cleft services are welcome to provide further feedback to the CRANE project team via crane@rcseng.ac.uk.

Appendix 1: Key Stakeholder Resources for Clinical Excellence Networks (CENs)



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September 2023

1. The Basics

- 1.1. Website - <https://www.crane-database.org.uk/>
- 1.2. Online enquiry - <https://www.crane-database.org.uk/contact/>
- 1.3. Twitter - [@CRANE News](https://twitter.com/CRANE_News)
- 1.4. Email - crane@rcseng.ac.uk
- 1.5. Phone - 02078696610
- 1.6. Database - white “CRANE Data Entry System” button found along the top of the website
<https://www.crane-database.org.uk/>

2. Database

- 2.1. Request an account - <https://www.crane-database.org.uk/professionals/request-an-account/>
- 2.2. Data dictionary - <https://www.crane-database.org.uk/resources/crane-data-dictionary/>
- 2.3. Data collection forms - from the same page as above for the data dictionary, scroll down to see - Forms 1 and 2 <https://www.crane-database.org.uk/resources/crane-data-dictionary/>
- 2.4. Consent forms and patient leaflets
<https://www.crane-database.org.uk/resources/information-leaflets-and-parental-consent-forms/>
- 2.5. Word version of guidance - <https://www.crane-database.org.uk/resources/guidance>
- 2.6. Video version of guidance - <https://www.crane-database.org.uk/resources/guidance-videos>
- 2.7. Live tables - available to those with database access. Log in, select ‘Live tables’ from the menu on the left hand side of the screen, then select the table you wish to view.

3. Annual report

- 3.1. Annual report and supplementary tables - <https://www.crane-database.org.uk/reports-home/> select the year you want. The Supplementary tables are beneath the image of the front cover of the report.
- 3.2. Patient and parent report - either from the ‘reports home’ click on the year you need e.g. [2022](#) select [summary for patient and parents/carers](#) or go to <https://www.crane-database.org.uk/reports/public>
- 3.3. Infographic - <https://www.crane-database.org.uk/resources/infographics>

4. Publications

- 4.1. Journal articles - <https://www.crane-database.org.uk/publications/journals>
- 4.2. Conference & meeting presentations - <https://www.crane-database.org.uk/publications/conferences>

5. Workshop and Webinar Summaries

- 5.1. Workshops and webinar summaries - <https://www.crane-database.org.uk/publications/workshops-and-webinars>