



CRANE Database

Tel: 020 7869 6610

E: crane@rcseng.ac.uk

W: www.crane-database.org.uk

CRANE Database Meeting: Making It Better Session

22 January 2024

1. Background

The 2023 CRANE Annual Report was published in December 2023. The January 2024 'Making it Better' session was open to all Cleft Service team members and was convened to provide stakeholders with an opportunity to reflect on the Annual Report, discuss what might be causing variability in rates between Cleft Services, share good practices resulting in positive outlier status (as per the [Outlier Policy](#)) for data completeness, identify and share barriers to data submission faced by services with negative outlier status, and provide key Database updates and developments.

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

1.1. Attendees

The meeting was facilitated by Craig Russell (CR) and Kate Fitzsimons (KF) from the CRANE Project Team. A total of 44 people attended, with all UK Cleft Services represented.

1.2. Aims and objectives

The overall aim was to provide stakeholders with an opportunity to share good practice and challenges relating to submission of CRANE data. The session was split into 4 parts:

- Changes to the CRANE Annual Report
- Sharing local experiences
- Q&A
- CRANE updates and key guides

2. Presentations

The sections below summarise the points covered by each speaker.

2.1. Craig Russell – Welcome and introduction [slides available]

- Welcome and aims of the session.
- Request to organisations sharing ONLY CRANE ID when liaising with us via email or the CRANE contacts forms. Sharing any Personal Identifiable Data (PID) is an information governance issue as we (CRANE) are outside of the NHS.
- New local action plan template is available for services.

2.2. Kate Fitzsimons – CRANE Annual Report 2023

- Overview of 2023 CRANE annual report structure
- Changes have been implemented to make the annual report easier to read and digest.
- Flow charts now appear at the beginning of the registry and 5-year outcome chapters. These show inclusions and exclusions.
- Coloured ring donuts introduced to illustrate data completeness and outcomes.
- Additional breakdowns of cleft type are provided: Sidedness of cleft lip, completeness of UCLP and BCLP, submucous cleft palate (smcp) alone and smcp + cleft lip.
- New funnel plots have been introduced in the registration chapter for data items that either show variability between services or are key indicators in early cleft care. The 'Notes' section indicates whether these are subject to outlier policy.
- Robin Sequence (RS)
 - Variability in reported rates between services.
 - CRANE identified labelling error with x-axis on RS funnel plot. This has now been corrected and updated report uploaded to website (version 1.1).
- Birth characteristics: Gestational age and birthweight. There appears to be a dichotomy in reporting, whereby services are either reporting these characteristics for a high percentage of their cases or they are really struggling with these data items. Are cleft services always collecting this information from referring maternity units?
- Antenatal diagnosis for clefts involving the lip. Although this reflects maternity care, we hope this information will encourage Cleft Services with poorer than expected antenatal diagnosis rates to engage with referring maternity services to identify barriers to timely diagnosis.
- Timely diagnosis (before or <24hrs of birth) for cleft palate alone. Although there is variability, there are no outliers. When we extend to <72hrs of birth, some units' rates improve substantially, indicating their referring maternity services may be doing later newborn checks. Information could be used to facilitate discussion with maternity services.
- Referral and contact time. There is a lot variability for referral time data completeness. Some units are negative outliers for contact within 24hrs of referral.
- This year, we have included the alert/outlier summary table in the Supplementary workbook, available alongside the annual report. This indicates whether a particular service is an alert/outlier for a particular data item that is subject to our outlier policy and specifies whether it is for data completeness and/or the actual outcome.

2.3. Peri Codling (Cleft Net East)

2.3.1. Rapidly turning around a low consent verification rate

- Missing consent data was affecting 5-year old speech and dental data on CRANE Database resulting in negative outlier status. This was identified in the 2023 preliminary report.
- To overcome negative outlier status the Trust:
 - identified missing consents for 2016, which seemed to be the problem year,
 - recruited admin support team,
 - identified children attending clinic appointments over the following 6 weeks where the admin staff were able to obtain consent,
 - allowed consent to be obtained over the phone or electronically, if necessary for those not attending clinic,
 - uploaded speech and dental data once consent was obtained for each child.
- All nursing staff now collect consent at birth to mitigate missing consent data in the long run.

2.3.2. Reflections on low PRS rate

- The service was previously unaware of the lack of PRS reporting. After exploring records, they identified that PRS was reported to CRANE for only 1/3 of their PRS cases, so under-reporting is why they are an outlier for PRS rates among CPO cases.
- Utilizing CRANE data form helps to ensure accurate data.

2.4. Helen Extence (South Wales)

2.4.1. Reflections on high PRS rates – Why are Pierre Robin Sequence rates high in South Wales?

- To reflect on their rates, they asked:
 - **Are we better at identifying PRS?** They have a clear pathway for these babies, managed in partnership with the Paediatric Respiratory Service Childrens Hospital for Wales since 2019. Prior to 2019, mild to moderate cases were managed by the cleft team through NG and positioning, but this was not as well documented and may have led to underreporting.
 - **Are we better at reporting PRS?** They have a good system in place, with the PRS diagnosis written on baby clinic letters, operation notes, and baby registration card, so it's easy to enter data. One member is responsible for inputting onto CRANE.
 - **Are we over-reporting PRS?** Currently they have a system in place including emphasis on PRS reporting. Looking at the CRANE Data dictionary, all three characteristics (Micrognathia, Glossoptosis + cleft palate) should be present. They would need to go back to 2020 data and verify that all cases meet the definition by CRANE.
 - **Do we have higher rates of PRS?** South Wales seem to have more PRS babies and less isolated straightforward cleft palate babies. Lead geneticist is not aware of a higher burden of genetic conditions causing PRS. Tom Jovik (specialist registrar) looking into the geography and epidemiology of CLP in South Wales. PRS had an incidence of 2.2 per 10,000 live births in South Wales. This is almost double the globally cited incidence rate.

2.4.2. Maintaining excellence in data completeness

- They attribute this to:
 - All round team effort
 - Good pro formas, which include gestational age, birth weight, referral time etc. on the new baby registration form and 5-year old height and weight and dmft scores on the 5 year old forms.
 - Good administration and organisation:
 - Admin support
 - List of all 5-year-olds from hospital database cross-checked with CRANE
 - 'Was Not Brought' policy that helps patients to attend MDT appointments
 - Designated 5-year and 10-year old audit clinics
 - Data inputting stars – experienced staff who enter data to CRANE
 - For speech completeness (positive alert on CRANE) – SLT assistant completes consensus listening forms at time of listening, inputs data and checks for missing data.
 - For Psychology completeness (positive alert on CRANE) – Clinical Psychologist and an Assistant psychologist (AP) attend clinics. AP inputs data and checks for missing data.
 - Consent verification (positive alert on CRANE) – consent obtained at baby clinic (6-8wks) and put on CRANE when secretary types the clinic letter.

2.5. Lyndsay Kirk (Scotland) – Achieving 100% data completeness for gestational age and birthweight.

- Scotland has multiple methods of recording for clinical purposes and they use the CRANE data collection form for registrations.
 - Referral form
 - Feeding assessment
 - Electronic patient record
- Each CNS is responsible for filling forms for their own caseload and all data are collated centrally on a single site by a co-ordinator, who transfers data. Any gaps and queries are identified and raised with CNS.

2.6. Natalie Matthews (West Midlands) – Challenges in submitting data to CRANE and plans to overcome these in the future

- Reason for outlier status / challenges
 - Didn't have a designated data coordinator
 - Backlog of patients caused by the pandemic
 - Staffing gaps
 - Time-consuming pressures from NHSE targets and deadlines
 - Local database was no longer fit for purpose – was able to put data in but unable to export it to then upload to CRANE
- Future plans to overcome challenges
 - Data coordinator role to be appointed
 - Psychology and orthodontic roles now appointed
 - Process for consent now implemented
 - About to trial a 5-year audit clinic
 - Implementation of EPIC & Plans to update / incorporate database
 - Hired a Data/Governance lead role

3. Q & A

- A few attendees requested copies of the proformas Wales are using for their 5 year clinics as well as their 'Was Not Brought' policy and PRS pathway. Helen kindly offered to share via email to those requesting these.
- This led some to question whether CRANE could hold these useful documents on their website so that other services could access them. Craig committed to discussing this with the CRANE project team and reporting back at the CFSGBI conference.
- Someone asked how staff manage using CRANE data collection paper sheets if they are a paperless service. An attendee replied saying their service scan these on the Electronic Patient Record.

4. Craig Russell - Database Developments

The sections below summarize recent and upcoming CRANE database developments.

4.1. Submucous Cleft

- The LAHSAL code is now independent from SMCP tick box, which allows for improved accuracy of cleft typing.

4.2. Total DMFT score

- This was previously reported but is now automatically calculated based on the individual element scores. This will limit data inconsistencies and improve the accuracy of data collection and reduce workload for local teams.

4.3. Psychology

- TIM score has been updated to collapse sub scores of 1 and 2.
- Psychology SDQ was not specific enough for cleft population and will no longer be collected for children born after 2017. Refer to Psychology CEN statement in 2023 CRANE Annual Report for more information on this.

4.4. Next Steps

- New Psychology and Audiology outcomes to be considered by CEN.
- Analyses of Newborn Hearing Screening Programme (NHSP) data linked to CRANE.

4.5. Quality Improvement Resources

- Local Action Plan
- Q&A Session on 7 February 2024 – recommended for those who regularly use the database and submit data
- Data Dictionary and Data Collection Forms (some of these are being updated to reflect recent database changes – these went live at the end of January 2024).
- Guides for CRANE database users
 - 11 guides on our website and 6 video demonstrations.
- Workbooks to be shared with each service listing CRANE ID's whose records need updating. Correcting these errors will improve data accuracy.

5. Important dates

Upcoming **data deadlines** are as follows:

CRANE data entry deadlines:

- Sunday 3 March 2024 – Preliminary report
 - Registrations for 2021 to 2023 births
 - 5-year outcomes for 2015 to 2017 births
- Sunday 30 June 2024 – Annual report

Dashboard data entry deadlines:

- Friday 8 March 2024 – Q3 2023/24
- Friday 14 June 2024 – Q4 2023/24

See the [data collection milestones for 2024](#) for full details of key dates. Remember to make use of CRANE resources to check your data, and contact crane@rcseng.ac.uk with any queries.

Join us on 7 February 2024 at 10:30-12:00 for a 'CRANE data Q&A' in advance of the March data extract for the preliminary report – suitable for anyone who records and submits data. An invitation for this even was sent on 11 December 2023. Contact the CRANE team to express interest in attending if you did not receive this invite.