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CRANE Database Meeting: CRANE 2024 Preliminary Report review

15 May 2024

1. Background

The Preliminary CRANE 2024 Audit Report, produced by the CRANE Project Team, was distributed to Cleft Services on 28 March 2024. The report presented data that was submitted to CRANE by 4 March 2024. The aim of the report is to give Cleft Services sight of preliminary data in advance of the 30 June 2024 data submission deadline for the CRANE Database 2024 Annual Report.

The Preliminary report presented a series of funnel plots showing each Cleft Service's position in relation to the national average. Consent, registration and early care information was provided for the 2021 to 2023 birth cohort, while 5-year outcomes were shown for the consented 2015 to 2017 birth cohort. The online event focused on the 5-year old cohort, as 5-year data completeness and outcomes are subject to the CRANE Outlier Policy.

The webinar was open to all UK Cleft Service team members, and was particularly relevant to Clinical leads and directors of Cleft Services and staff 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 suggestions raised during the event.

1.1. Aims and objectives of the online event
- Review the data presented in the CRANE 2024 Preliminary report;
- Highlight available resources to improve data quality;
- Review the outlier process for 2024;
- Answer questions in advance of the 30th June 2024 data submission deadline;
- Discuss how services could improve the quality and reliability of the outcomes presented.

1.2. Attendees
The event was facilitated by Craig Russell (CR) and Kate Fitzsimons (KF) from the CRANE Project Team and was attended by over 40 people: Representatives were present from different specialties within Cleft Services in England, Wales, Northern Ireland and Scotland, as well as CRANE team members.

2. Presentation content
- Aims and objectives for the day
- Welcome and introduction
- Preliminary report inclusions/exclusions
- Reminder that the supplementary tables contain the raw data used to generate funnel plots

- Overview of how to interpret funnel plots
- Data included in the Preliminary CRANE Audit Report 2024 and covered in the meeting:
  1. Registration information – including consent verification, cleft type, RS among CPO patients, and syndromes.
  2. Outcomes at 5 years – child growth, dental health (and dental health data completeness at 10 years), facial growth, speech and psychology.
  3. Overview of preliminary report outliers and alerts for 2024.
- Key resources to improve data quality, including live tables, guides/video demonstrations, and data checks workbooks
  1. Updates to live tables to reflect current reporting cohort for consent and outcomes tables
  2. Guidance on website
     - Guides – such as those supporting exports and transfers (by push pull).
     - Videos – such as those support identify those without verified consent, and with missing data.
  3. Data checks workbook and queried LAHSAL codes – circulated February 2024
     If support is needed to understand how to best explore your data held on CRANE, we recommend joining our next webinar session on 24 May.
- Questions from attendees
  o How can looked after or adopted children be consented? The current guardians of the child can provide consent for the child. CRANE FAQ #10 provides guidance on what happens when a child is adopted.
  o Should autism and ADHD be recorded as a syndrome/significant additional diagnosis in CRANE? CRANE confirmed that these conditions should NOT be recorded as syndromes/significant additional diagnoses under the syndromes tab on the CRANE database. If a child is unable to complete an outcome assessment because of these conditions, 'clinically contraindicated' can be entered as a 'reason outcome not collected'. Guidance about the recording of syndromes is available here.
  o How do we record a lack of clinics during COVID as a reason for not collecting outcomes? 'Other reason' should be selected under 'reason outcome not collected' and *COVID* can be entered as free text.
  o Can children be audited outside of their fifth year? Auditing patients from their 5th birthday and in advance of their 6th birthday has been agreed as the standard by all Clinical Excellence Networks and the Cleft Development Group. Crane does not exclude children from outcome reporting if either the date of assessment is missing or if it is outside these times. Some services will still add collected data and others will not do the assessment. CRANE calculates the percentage of children assessed at the correct age for each outcome and this is presented in the Supplementary tables. Should there be significant change to the proportion audited within the ascribed period then CRANE will inform the CDG and discuss appropriate action. For peer-review publications, CRANE will only include children assessed during their fifth year.
  o What counts as an 'eligible' case for outcomes? Only consented cases who are alive at 5 years are eligible for outcome reporting and included in the 'number of eligible cases' on the x-axis of the data completeness funnel plots. Some outcomes have additional criteria. For example, speech outcomes are reported for non-syndromic children with a cleft affecting the palate, and five-year-old index is reported only for those with a complete UCLP. Eligibility is clearly stated in each section of the report and in the supplementary tables.
  o Kana Miyagi, a cleft consultant at Addenbrooke's hospital in Cambridge (Cleft Net East) wished to share learning about extracting data from a service's own hospital system (e.g. EPIC) and manipulating it to facilitate importing into the CRANE Database, i.e. creating a process to facilitate interoperability between the two systems. Kana asked that the CRANE team share the contact

details for the data managers at other Cleft Services to contact them to understand the processes teams have for preparing their data for submission to CRANE. Due to GDPR/good IG practice, the CRANE team are unable to do this without explicit consent from individuals. Those interested in supporting this shared learning were encouraged to reach out to Kana directly. It was also highlighted that most cleft team coordinators are listed on CLAPA's website. Following this event, the CRANE team confirmed that Kana was happy for us to include her contact details in this summary, so that potential collaborators may choose to contact her at kana.miyagi@nhs.net should they wish to share their processes.

- Summary by Craig Russell
  - o Outliers and alerts in 2024
  - o CRANE 2024 Timeline
- Reflections on preliminary report
  - o Improve CRANE for all
  - o Data Completeness
  - o Variability in data completeness / outcomes
- Next meetings:
  - o 'Question and Answer' webinar takes place on **24 May 2024 at 10:00**
  - o 'Making it better 2025' with invited speakers **on 20 January 2025 from 10:30**

As the Preliminary report is not distributed publicly, the slides for this presentation are available to Cleft Services only. Please do not share beyond your cleft team.

3. Next steps

Services were encouraged to access key [resources](#) on the CRANE website to help achieve good levels of data completeness and accuracy in advance of the following upcoming data submission deadline: 30 June 2024.

Teams are welcome to provide further feedback via crane@rcseng.ac.uk.