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CRANE Database Meeting: Making It Better Session

30 January 2023

1. Background

The 2022 CRANE Annual Report was published in December 2022. The January 2023 Making it Better session was convened to provide stakeholders with an opportunity to share views and reflect on the Annual Report; answer questions in advance of the data submission deadline for the 2023 preliminary report; identify barriers to data submission faced by services with negative outlier status as per the Outlier Policy piloted in 2021; share lessons learned from services with positive outlier status; and provide key Database updates and developments.

This session was open to all cleft service team members, and particularly relevant to those involved in 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 at the consultation meeting.

1.1 Attendees

The meeting was facilitated by Craig Russell (CR), Jibby Medina (JM), Sophie Butterworth (SB) and Kate Fitzsimons (KF) from the CRANE Project Team. A total of 75 people attended the session: 70 representatives from different specialties within all regional cleft services (see **Table 1**) and five CRANE team members. Six of the representatives from different specialties within regional cleft services gave presentations based on their experiences.

Table 1. Number of attendees by cleft service

Cleft services – in England, Wales and Northern Ireland	Number of attendees
Newcastle	4
Leeds	2
Liverpool	5
Manchester	4
Liverpool & Manchester affiliations	3
Trent	6
West Midlands	1
Cleft Net East	8
North Thames	9
The Spires	6
South Wales	3
South West	2
Evelina London	4
Northern Ireland	5
Scotland	5
Not possible to assign to a cleft service	3
CRANE Project Team	5
Total	75

1.2   Aims and objectives

Provide stakeholders with an opportunity to share views on the outlier process experienced and reported on in 2022, including:

- discussing barriers to data submission faced by cleft services, and
- learning lessons from services achieving positive outlier status – particularly for consent verification and outcome data completeness indicators.

2.   Presentations

The sections below summarise the points covered by each speaker.

2.1   Craig Russell – Welcome and introduction [slides available]

- Aims of the session.
- Recap of the key findings from the 2022 Annual Report, with an emphasis on variability between services and how this can be improved.
- The importance of data completeness to ensure the conclusions drawn from analysis of the data are robust.
- The ambition to introduce risk adjustment to the analysis to help understand and address the reasons for variability, with the aim of raising all services to match the best performers.
- The potential for cleft teams to use the findings to approach managers regarding resources, where required (e.g. where a service has negative outlier status).

2.2   Diane Phare (Manchester) – on consent verification

- Where there is an antenatal diagnosis:
  - At the first meeting, the team provides parents with an information pack that includes the CRANE leaflet and consent form.
  - Parents are advised there will be an opportunity to discuss CRANE more when the baby is born.
  - Parents often bring the completed form to the first appointment.
- Where the diagnosis takes place at birth, the same pack is provided. Parents are talked through CRANE and the consent form is left with them to reflect on.
- If a patient who is coming to the clinic has not yet provided consent, this is flagged in the system for the team to bring up in clinic.
- Once a month, the cleft coordinator goes through all babies and advises if there is any consent missing, which is then followed up.

2.3   Pamela Larmour (Belfast) – on dental outcome data completeness [slides available]

- All data are stored in a bespoke Excel spreadsheet showing cleft type and related information, the date on which data were collected and any issues with data collection, including the reason for this.
- The service runs age-specific clinics, making it easy to keep an eye on all patients in a specific cohort.
- A data collection form is used in each clinic.
- The information on each form is then entered onto the Excel spreadsheet and into CRANE, including why an outcome has not been collected where this is the case.
- At the start of each year, information is downloaded from CRANE, and if any data are missing the reason for this is checked and remedied where possible.
- A final data check is carried out before submission to CRANE.

2.4 Melanie Stern (Trent) – on facial growth outcome data completeness [slides available]

- The cleft service functions on a hub and spoke model, with Nottingham as the hub.
- The location of spokes is based on patient populations, to reduce travel burden. All orthodontic records are taken by the spoke orthodontist.
- Pre-COVID, the service achieved 100% data completeness – a unique year. Face-to-face appointments were back up and running by July 2020.
- The hub issues lists of all patients needing appointments to the spokes.
- All members of the team are able to take records and are familiar with cleft patients, minimising obstacles to data collection.
- Before the clinic, the data are cleaned by checking/correcting LAHSHAL codes for all patients and reviewing CRANE consent.
- Appointments are sequenced so the orthodontic check is last, avoiding issues with children potentially being upset by the process of taking photographs/dental impressions.
- Children are rewarded with stickers, toys or other small gifts at each station.
- Cancellations or 'was not brought' (WNB) are followed up and rescheduled ASAP, in conjunction with safeguarding where needed.
- After the appointment, various methods are used to protect the data:
  - Photographs and measurements are emailed directly to the lead orthodontist.
  - Hospital mail is avoided – instead, trainees carry out person-to-person transfer of plaster models.
  - There are three sets of photographs and models created: one for the hub, one for the spoke and one sent for external validation.
  - The value of data is reinforced by regular feedback to the MDT.

2.5 Michaela Rowe (Wales) – on child growth and speech outcome data completeness [slides available]

- Children are booked for the 5-year clinic at 5 years 6 months of age, allowing enough time for them to be re-booked before they turn 6 if needed (eg, cancellations, WNB).
- The service has a robust WNB policy to allow for follow-up and re-booking.
- A clinic list is circulated well before each clinic to ensure staff are aware of who's due to attend.
- All clinics are held on one site and all records are stored at the same site.
- The same people input all data.
- The same person (the dental nurse) takes the growth measurement – this field is typically not well filled in, and having a named person has been important in improving data collection.
- A bespoke data collection form has been developed which all clinicians complete during the clinic; it then goes to the secretary who enters the data on CRANE.
- Speech data are taken at the clinic. A consensus listening exercise is then undertaken before the data is recorded and entered onto CRANE. To ensure data accuracy and completeness, the person entering the data must have been present at the consensus listening.

2.6 Fiona McKendrick (Newcastle) – on psychology outcome data completeness

- A key factor in ensuring data completeness is the role of the data coordinator and clinic coordinator, who keep track of all children and ensure they are booked in for their 5-year audit in good time (to allow for cancellations and WNB to be re-booked).
- Audit clinics used to be run so that all children were seen for their 5-year audit in one clinic. Now patients are slotted in as needed which seems to be working well.
- In advance of each clinic, the data coordinator prepares a bespoke data collection form for each healthcare professional setting out what needs to be collected. The healthcare professional completes this and returns it to the data coordinator, who enters the data (and chases up any missing components).
- Note that Newcastle is a well-resourced service and always has a psychologist present at the clinic, which is a significant benefit in terms of supporting data completeness.

2.7 Priya Haria (North Thames) – on the service's response to the CRANE outlier process [slides available]

- North Thames was flagged as a negative outlier for data completeness across psychology, speech and language therapy and paediatric dentistry. The presentation looked at the background to this and the actions taken by the service as a consequence.
- As background, in 2017 the previous Microsoft Access database used by the cleft team was replaced by EPIC. When submitting data for CRANE, clinicians noticed that information on CRANE and EPIC did not match, including LAHSAL code and medical history.
- A LAHSAL code audit/quality improvement (QI) exercise is being undertaken looking at differences between EPIC and CRANE and correcting data as appropriate, checking:
  - LAHSAL code – using operation notes, clinical photographs
  - Medical history/syndromes
  - If patients were still with the North Thames service
- Efforts to address the issues include:
  - Retraining clinicians and the administrative team on entering information in EPIC
  - Developing a standard operating process (SOP) to ensure the same process is followed when entering information
  - Repeating the audit cycle
- The issues behind the negative outlier status included staffing, data entry, did not attends (DNAs), lack of cooperation and deceased patients not being recorded as such.
- The response to the negative outlier status includes:
  - Ensuring time is devoted to identifying the missing data
  - Undertaking a QI exercise to ensure the dataset is correct (appropriate patients attending audit appointments, information on transfer of care, medical history etc… updated to CRANE)
  - Ensuring patients are not lost to follow-up, through pathways in EPIC and access plans, and a better process to follow up patients who cancel/DNA
  - Calibration of paediatric dentist for dmft recording is required
  - Improving staffing processes in psychology, and recruitment of paediatric consultant

2.8 Key messages

- Provide information on CRANE and the consent process early to improve rates of consent verification.
- Perform regular data checks throughout the year to flag missing data and update.
- Use data collection forms to avoid missing important data fields.
- Maintain good communication with spoke sites to ensure quality of data collected within them is consistent with the hub site.
- Offer clinic appointments shortly after children turn 5 to allow for rescheduling if appointments are cancelled or not attended.

3. Recap of recent and upcoming CRANE developments (Jibby Medina, Sophie Butterworth and Kate Fitzsimons, Craig Russell)

The capture of:

- Syndromes and additional diagnoses – January 2021
- Ethnicity – March 2021
- Developmental defects of enamel (DDE) – May 2022

Next steps:

- Psychology outcomes at 10 and 15 years – noting that similar fields have been added for other areas of cleft care but are not well used

- LAHSAL and LAHSHAL work – looking at whether increasing the complexity of the data leads to a reduction in data quality, to inform whether CRANE makes the transition
- Linkage to surgical procedures via Hospital Episode Statistics (HES) – noting that a secure funding and contractual arrangement will be needed to facilitate this
- Inclusion of new orthodontic and audiology outcomes – to be discussed with relevant Clinical Excellence Networks (CENs)
- Linkage to Newborn Hearing Screening Programme (NHSP)

QI resources to help improve your data:

- 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.
- The 11 'how-to' guides and 6 video demonstrations are useful resources for understanding how to use the CRANE database.
- 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.
- Some CENs have expressed concerns about patients from other services being included in outcome reporting – for managing transfers, use the relevant guide and video demonstration.
- Only children born in and resident in the UK should be recorded in CRANE. See FAQ #11 on our website for more detail.

4.   Important dates

Upcoming **data deadlines** are as follows:

- Friday 24 February 2023 – Q3 2022/23 Dashboard
- Monday 3 April 2023 – extract for preliminary report, which will cover:
  - o 5-year outcomes for 2014-16 births
  - o Registrations for 2022-22 births.

Remember to make use of CRANE resources to check your data, and contact crane@rcseng.ac.uk with any queries.

See the data collection milestones for 2023 for full details of key dates.

Join us on 28 February 2023 at 10:30-12:00 for a 'CRANE data Q&A' in advance of the April data extract for the preliminary report – suitable for anyone who records and submits data.

Contact the CRANE team at crane@rcseng.ac.uk to express interest in attending.

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