

Cleft Team Local Action Plan for responding to CRANE 2020 Annual Report Recommendations

The cleft team should complete the following details to allow for ease of review:

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|--------------------|--|
| Audit title & aim: | The Cleft Registry and Audit NETWORK (CRANE) Database. Evaluates and reports on the delivery of cleft services to children in England, Wales and Northern Ireland with the congenital abnormality of cleft lip and/or palate. |
| Cleft care team: | |
| Audit lead: | |
| Action plan lead: | |

When making your action plan, make sure to keep the objectives SMART – **S**pecific, **M**easurable, **A**ssignable, **R**ealistic, **T**ime-related.

Note: Data relating to each recommendation listed below can be found in the ‘**CRANE 2020 Annual Report**’ here:

<https://www.crane-database.org.uk/reports/crane-database-2020-annual-report/>

| Key 1 (for the action status) |
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| 1: Awaiting plan of action |
| 2: Action in progress |
| 3: Action fully implemented |
| 4: No plan to action recommendations (state reasons) |
| 5: Other (provide information) |

| Key 2 (for the action priority) |
|---|
| HIGH: requires urgent action, and local audit |
| MEDIUM: requires prompt action, and consider local audit |
| LOW: requires no immediate action or local audit |

| No. | Recommendation (Guidance available – Full detail on final page) [Related report section] | Action required? (Yes/No; state intended action OR reason for no action) | Action activities | | | |
|--------------------|--|---|---------------------------|-----------------|-----------------------|-------------------------|
| | | | Responsible individual(s) | Agreed deadline | Status (see Key 1) | Priority (see Key 2) |
| Rec 6 ¹ | <p>Contact with cleft care teams</p> <p>Cleft care teams should continue to work with referring obstetric, midwifery and neonatal units to improve timeliness of diagnosis and early referrals.</p> <p>[Chapter 3, Section 3.5]</p> | <p><u>Suggested actions:</u></p> <p><i>Cleft care teams should agree strategy to ... improve timeliness of diagnosis for children with a cleft in clinic, such as...</i></p> <ol style="list-style-type: none"> 1. Education plan for engagement with referring sonography / obstetric and neonatal units 2. Education activity within local nursing and midwifery courses 3. Education activity within local medical school paediatric curriculum (part of new baby exam education team) 4. Education activity within local GP training scheme <p><i>Consider creating a timely detection of clefts focus group to understand how to ensure local cleft service is meeting patients' needs by best disseminating knowledge on optimal new baby exam.</i></p> | | | | |
| Rec 7 | <p>Contact with cleft care teams</p> <p>Cleft care teams with high levels of referrals within 24 hours should share their best practise recommendations.</p> <p>[Chapter 3, Section 3.5]</p> | <p><u>Suggested actions:</u></p> <p><i>Cleft care teams with low levels of referral within 24 hours should nominate an individual(s) to reach out to a cleft care team with high levels of referrals within 24 hours, to learn from their best practise – and share this learning within their own team.</i></p> | | | | |

¹ See Appendix 1 for detail on recommendations 1 to 5, as well as all other recommendations for CRANE and the research community.

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| Rec 8 | <p>CRANE Consent</p> <p>Cleft care teams should review their procedures to identify reasons for low rates of verified consent, and ensure that CRANE consent status is recorded for every child with a cleft.</p> <p>[Chapter 3, Section 3.6]</p> | <p><u>Suggested actions:</u></p> <p><u>Ensure the designated individual(s) for managing CRANE data feeds is aware of the location and correct completion of the consent information in the CRANE Database. [Training]</u></p> <p><u>/ Make sure that the data manager within your organisation is aware to fill in this field for all patients with a cleft.</u></p> <p><u>Perform local audit to understand the reasons if parts of consent section are incomplete, and take action to increase data completeness. (whole team responsibility)</u></p> <p><u>Discuss what steps could be taken within your team to improve recording of consent, if your audit finds low levels of data completeness.</u></p> <p><u>Identify local practitioner to reach out to high performing team to explore how their approach to consent collection and documentation works</u></p> | | | | |
| Rec 10 | <p>Child growth at 5 years</p> <p>Cleft care teams should aim to assess children’s weight and height around the age of five years and improve the reporting of these measures in the CRANE database. This will facilitate more meaningful comparisons between subgroups in the future.</p> <p>[Chapter 4, Section 4.1]</p> | <p><u>Suggested actions:</u></p> <p><u>Does your team have a protocol for how X outcome data are systematically collected, recorded and documented on CRANE Database?</u></p> <p><u>Look at how your cleft care team compares to the figures for all/ other teams in... the AR / Audit Day Reports / Outcomes Report (behind the log-in).</u></p> <p><u>Does this reflect what happens in your organisation? If not, what steps can you take to improve assessment of X outcome? What action needs to be taken?</u></p> <p><u>[Consider incorporating virtual MDT meeting where all audit data is reviewed on CRANE to ensure that whole team happy with record]</u></p> | | | | |

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| Rec 11 | <p>Dental health at 5 years</p> <p>All children with a cleft should have a recommended care plan established by collaborative work between the families' General Dental Practitioner (GDP) and cleft care teams to: (a) treat the child as per the high-risk category of the dental toolkit (delivering better oral health), (b) provide local dental care (GDP led), and (c) provide age-specific dental development assessments and advice (cleft care team led).</p> <p>[Chapter 4, Section 4.2]</p> | <u>As for Rec 10</u> | | | | |
| Rec 13 | <p>Speech at 5 years</p> <p>Information given to parents by cleft care teams about expected speech outcomes should take into account the child's cleft type.</p> <p>[Chapter 4, Section 4.4]</p> | <u>As for Rec 10</u> | | | | |
| Rec 15 | <p>Psychology screening at 5 years</p> <p>Cleft care teams should aim to see all children and families at age 5, undertake a psychological screen and ensure psychological support is provided if appropriate (to be recorded as a TIM score).</p> <p>[Chapter 4, Section 4.5]</p> | <u>As for Rec 10</u> | | | | |

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| Rec 17 | <p>Timing of repair, number of surgeries and speech at 5 years</p> <p>For the most favourable speech outcomes: Children should have their palate repaired by cleft surgeons before they are 13 months old. [Chapter 5, Section 5.2]</p> | <p><u>Suggested actions:</u></p> <p><i>Does your team locally audit age at completion off primary palate repair?</i></p> <p><i>Is there a process in place to highlight patients still waiting for palate repair beyond 9 months of age such that there on going care can be optimised to facilitate repair before 13 months</i></p> <p><u>Look at how your cleft care team compares to the figures for all/ other teams in... the AR / Audit Day Reports...</u></p> <p><i>Does this reflect what happens in your organisation? If not, what <u>steps can you take to...</u>? What <u>action</u> needs to be taken?</i></p> | | | | |
| Rec 18 | <p>Timing of repair, number of surgeries and speech at 5 years</p> <p>Where possible, surgeons should aim to repair the cleft palate in one procedure (not including vomer flap at time of lip repair). [Chapter 5, Section 5.2]</p> | <p><u>Surgical, nursing and paediatric members of team to review 2020 report section on number of repairs and agree strategy to optimise pre-operative surgical planning to ensure active decision on timing of repair is made to reduce likelihood of 2or 3 stage repairs</u></p> | | | | |
| Rec 20 | <p>Deprivation and dental health at 5 years</p> <p>Cleft care teams should have mechanisms in place to identify and target children from the most deprived groups to ensure they receive help, such as Sure Start, to facilitate their access to appropriate dental care and advice. [Chapter 5, Section 5.3]</p> | <p><u>As for Rec 17?</u></p> <p><u>Does your team have process / strategy to identify high risk cases from low socio-economic backgrounds to optimise dental outcomes?</u></p> <p><u>Have you considered tailored / prescribed difference in pathway to address the situation of poorer outcomes in lower socio- economic groups</u></p> <p><u>Consider stratified follow up pathway taking early decisions at appropriate age to stratify to low / medium and high-risk follow up pathways targeting resource where it will be most beneficial</u></p> | | | | |

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| Rec 21 | <p>Data quality (Completeness of data items) Cleft care teams, Clinical Excellence Networks (CENs) and CRANE should work together to identify barriers to collecting and submitting data. [Throughout report]</p> | <p><u>Suggested actions:</u> <i>Identify an individual(s) / clinician responsible for reviewing and feeding back, to staff within their cleft care teams, on their data returns.</i> <i>/ Identify a senior clinician to provide advice on data accuracy, data flows and the use of local and national data in governance activities. Is there a clinical lead for this?</i> <u>Ensure your MDT team know who in their organisation is responsible for ensuring data is routinely uploaded.</u> <i>Ensure there is a good link with this person/team.</i></p> <p><i>All data from your organisation requires review and sign-off from an allocated individual; be clear on who this is and make them aware of this audit.</i></p> | | | | |
| Rec 22 | <p>Data quality (Completeness of data items) Cleft care teams should pay particular attention to assessing outcomes and reporting these to CRANE. [Throughout report]</p> | <p><u>Suggested actions:</u> <i>Look at the data completeness / ensure a nominated person looks at the data completeness of these key data items for your organisation using CRANE Database Tables (behind the log-in) and exports; the CRANE data completeness target is a minimum of 90% for all key data items.</i> <i>All cleft care teams can access the CRANE Database to see information on their data uploads in real time.</i></p> <p><i>Does your team have a <u>protocol</u> for how all outcome data are recorded?</i></p> <p><u>Look at how your cleft care team compares to the figures for all/ other teams in... the AR / Audit Day Reports / Outcomes Report (behind the log-in).</u> <i>Does this reflect what happens in your organisation? If not, what <u>steps can you take</u> to improve data completeness? What <u>action</u> needs to be taken?</i></p> | | | | |

Appendix 1: Recommendations from the 2020 report for CRANE and the research community

Registrations in CRANE (Chapter 3, Section 3.1)

1. CRANE will engage with the nursing Clinical Excellence Network (CEN) to ensure better assessment and recording of registrations.
2. CRANE will continue to record cleft births and validate case ascertainment using external datasets.

Timely diagnosis (Chapter 3, Section 3.2 & 3.3)

3. CRANE will seek to collaborate further with clinical and non-clinical partners to identify ways of improving the timely diagnosis of CP within 24 hours of birth.

Gestational age and birth weight (Chapter 3, Section 3.4)

4. The research community should validate and further investigate the apparent association between cleft-affected pregnancies and prematurity at birth.
5. CRANE will engage with the RCM and Royal College of Obstetricians and Gynaecologists (RCOG) to communicate our findings.

CRANE Consent (Chapter 3, Section 3.6)

9. CRANE will continue to work with cleft care teams and the Nursing CEN to improve consent status verification.

Facial growth at 5 years (Chapter 4, Section 4.3)

12. The research community should undertake to compare UK facial growth outcomes with those in other countries.

Speech at 5 years (Chapter 4, Section 4.4)

14. The research community should undertake to develop risk stratification / adjustment models for analysing speech outcomes among children with a cleft

Incidence of cleft (Chapter 5, Section 5.1)

16. The research community should undertake to validate these findings using the HES dataset and case ascertainment techniques.

Timing of repair, number of surgeries and speech at 5 years (Chapter 5, Section 5.2)

19. The research community should validate these findings whilst controlling for potential confounders.