

Cleft Team Local Action Plan for responding to CRANE 2021 Annual Report Recommendations

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

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 2021 Annual Report**’ here:

<https://www.crane-database.org.uk/reports/crane-database-2021-annual-report/>

Key 1 (for the action status)

- 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

Please note: The recommendations listed below are those for action by cleft services.

Recommendations #1 to #3, #5 to #6, #10, #14, #16, #18 and #21 are not listed as they are actions for the CRANE team and/or other/a wider group of stakeholders.

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 4	<p>Gestational age and birth weight</p> <p>Cleft services should review procedures to ensure processes are in place to record and submit data on gestational age and birth weight. To track association of prematurity and low birth weights with clefting.</p>	<p><i>Cleft services should consider assigning an individual the responsibility of ensuring that this information is collected and submitted. Where a services data returns are low they should reach out to high returning services and learn from their successes, disseminating learning locally and initiating a local plan to correct data incompleteness that is applicable to local health care resources</i></p>				
Rec 7 ¹	<p>Contact with cleft services</p> <p>Cleft services should continue to work with referring obstetric, midwifery and neonatal units to improve timeliness of diagnosis and ensure early referrals. [Chapter 3, Section 3.5]</p> <p>Indicators: #3 & #4</p>	<p><u>Suggested actions:</u></p> <p><i>Cleft services should agree strategy to ... improve timeliness of diagnosis for children with a cleft, such as...</i></p> <ol style="list-style-type: none"> 1. <i>Education plan for engagement with referring sonography / obstetric and neonatal units</i> 2. <i>Education activity within local nursing and midwifery courses</i> 3. <i>Education activity within local medical school paediatric curriculum (part of new baby exam education team)</i> 4. <i>Education activity within local GP training scheme</i> <p><i>Consider creating a timely detection of clefts <u>focus group</u> to understand how to ensure local cleft service is meeting patients' needs by best disseminating knowledge on optimal new baby exam.</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>Contact with cleft services</p> <p>Cleft services with high levels of referrals within 24 hours of diagnosis should share their best practise recommendations. [Chapter 3, Section 3.5]</p> <p>Indicators: #3 & #4</p>	<p><u>Suggested actions:</u></p> <p><i>Cleft services with low levels of referral within 24 hours should <u>nominate an individual(s) to reach out to a cleft services with high levels of referrals within 24 hours of diagnosis, to learn from their best practice – and share and implement this learning within their own team.</u></i></p>				
Rec 9	<p>CRANE Registration and Consent</p> <p>Cleft services 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. [Chapter 3, Section 3.6]</p> <p>Indicator: #5</p>	<p><u>Suggested actions:</u></p> <p><i><u>Cleft teams should assign individual to do annual local case ascertainment exercise (comparing registered patients to alternate local data source. Correcting any registrations that not completed</u></i></p> <p><i><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></i></p> <p><i><u>/ Make sure that the data manager within your organisation is aware to fill in this field for all patients with a cleft.</u></i></p> <p><i><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></i></p> <p><i><u>Discuss what <u>steps</u> could be taken within your team to improve recording of consent, if your audit finds low levels of data completeness.</u></i></p> <p><i><u>Identify local practitioner to reach out to high performing team to explore how their approach to consent collection and documentation works</u></i></p>				

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Rec 11	<p>Child growth at 5 years</p> <p>Cleft services should aim to assess children’s weight and height at age five and improve the reporting of these measures in the CRANE database. This will facilitate more meaningful comparisons between subgroups in the future. [Chapter 4, Section 4.1]</p> <p>Indicator: #6</p>	<p><u>Suggested actions:</u></p> <p><i>Does your team have a <u>protocol</u> for how these outcome data are systematically collected, recorded and documented on CRANE Database?</i></p> <p><i>Has a specific individual been assigned responsibility to ensure collection / submission of these data points?</i></p> <p><u>Look at how your cleft services compares to the figures for all/ other teams in... the Annual Report / Audit Day Reports / Outcomes Report (behind the log-in).</u></p> <p><i>Does this reflect what happens in your organisation? If not, what <u>steps can you take</u> to improve assessment of <u>these outcomes</u>? What <u>action</u> needs to be taken?</i></p> <p><i>Where collection / submission low assigned individual should reach out to cleft services with high data completeness and share learning locally, champion introduction of similar processes applicable to the local healthcare environment</i></p> <p><i>[Consider incorporating virtual MDT meeting where all audit data is reviewed on CRANE to ensure that whole team happy with record]</i></p>				

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Rec 12	<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 services 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> <p>Indicators: #7 & #8</p>	<u>As for rec 10</u>				
Rec 13	<p>Facial growth (for children with complete UCLP)</p> <p>Cleft Services should see all children age 5 with complete UCLP and take records of facial growth (impressions or photographs). Records should be shared with national co-ordinator and assessed using the 5-year index with results recorded on the CRANE Database.</p> <p>Indicator: #9</p>	<u>As for rec 10</u>				
Rec 15	<p>Speech at 5 years</p> <p>Information given to parents by cleft services about expected speech outcomes should take into account the child's cleft type.</p> <p>[Chapter 4, Section 4.4]</p> <p>Indicators: #10, #11 & #12</p>	<u>As for Rec 10</u>				

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Rec 17	<p>Psychology screening at 5 years</p> <p>Cleft services 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> <p>Indicators: #13 & #14</p>	<u>As for Rec 10</u>				
Rec 19	<p>Congenital malformations in children born with a cleft</p> <p>Given the frequency of certain structural malformations, clinicians should consider standard screening for children with a cleft</p> <p>[Chapter 5, Section 5.1]</p>	<p><u>Suggested actions:</u></p> <p><i>Does your team know how many children within your care have a structural malformation?</i></p> <p><i>What processes are in place to check this and add this information to the CRANE database?</i></p> <p><i>Do you know how many patients within your service are referred to see a paediatrician or geneticist?</i></p> <p><i>How do your numbers compare to those in other centres, what steps could you take to improve detection? What <u>action</u> needs to be taken?</i></p>				
Rec 22	<p>Is there a difference in cleft-related speech outcomes between girls and boys at age 5</p> <p>The child's sex should be factored into risk adjustment models when reporting cleft-related speech outcomes at 5 years.</p> <p>[Chapter 5, Section 5.3]</p>	<p><u>Suggested actions:</u></p> <p><i>Do you ensure patient sex is recorded within the CRANE database?</i></p> <p><i>Does your team have a process / strategy to identify children at higher risk to optimise speech outcomes?</i></p> <p><i>Have you considered a tailored pathway to address poorer speech outcomes in boys? Taking early decisions at an appropriate age to target resource where it will be most beneficial.</i></p>				

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Rec 23	<p>Data quality (Completeness of data items)</p> <p>Cleft services should pay particular attention to assessing outcomes to report these to CRANE. [Throughout report]</p>	<p><u>Suggested actions:</u></p> <p><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 Medium term CRANE target for data completeness is a minimum of 90% for all key data items. (Currently working within 3 standard deviations of national mean to allow services to adapt to introduction of outlier policy and implications</i></p> <p><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><i>Look at how your cleft service compares to the figures for all/ other services in... the Annual Report / Audit Day Reports / Outcomes Report (behind the log-in).</i></p> <p><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>				

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Rec 24	<p>Data quality (barriers to participating in national clinical audit – data collection and submission)</p> <p>Cleft services, Clinical Excellence Networks (CENs) and CRANE should work together to identify barriers to collecting and submitting data.</p> <p>[Throughout report]</p>	<p><i><u>Suggested actions:</u></i></p> <p><i><u>Identify an individual(s) / clinician responsible for reviewing and feeding back, to staff within their cleft service, on their data returns.</u></i></p> <p><i><u>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?</u></i></p> <p><i><u>Ensure your MDT team know who in their organisation is responsible for ensuring data is routinely uploaded.</u></i></p> <p><i><u>Ensure there is a good link with this person/team.</u></i></p> <p><i><u>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.</u></i></p>				

Appendix 1: Recommendations from the 2021 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)

5. The research community should validate and further investigate the apparent association between cleft-affected pregnancies and prematurity at birth.
6. 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)

10. 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)

14. 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)

16. 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)

18. 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)

21. Surgical and Speech and Language Therapy CENs should agree whether to exclude children with congenital malformations from between-centre comparisons in speech outcome reporting in the future.