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CLEFT **REGISTRY** & **AUDIT NETWORK**

CRANE Making it Better learning event

7 February 2022



C Russell and J Medina

On behalf of the CRANE team



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Welcome and introductions

CRANE key timepoints



CRANE



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RCS System / IT support lost
CEU re-dev of Database & Website

GDPR enacted:
Emphasizing importance of good IG

Website Re-dev

CRANE's 22nd year:
Compliance with the national data-opt outs

2005

CEU
commissioned to run CRANE

2011

Linkage to HES established
Making data completeness of identifiers essential

2014

Linkage to NPD established

2015

Northern Ireland officially joins
Start exploring other linkages

2016

2018

IG

2020

2022

CRANE Reporting

Evaluation and reporting on the delivery of cleft services.

Reporting activity:

- Registry information
- Audit outcomes
- Research



Annual Report 2021

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CRANE is a national registry and clinical audit. It aims to evaluate and report on the delivery of cleft services to children in England, Wales and Northern Ireland with the congenital abnormality of cleft lip and/or palate. This year's report focuses on data collected over the 3 years prior to the COVID-19 pandemic's impact, and summarises information on the 1st year impacted by the pandemic.

Registry Information

21,865	The total number of children registered in CRANE, over the last 21 years, since 2000.		Cleft palate diagnosis times are improving, with more than ¾ of babies with a cleft diagnosed in the first 24 hours after birth, despite the impact of COVID-19 on services.
898	Number of registrations in 2020, the first year impacted by the COVID-19 pandemic.		83% of families were referred to a cleft team within 24 hours of birth and 96% of families received contact within 24 hours of referral.
86%	of babies with a cleft were born at term (>37 weeks). This compares to 92% in the general population.	98%	agreed to the collection of outcome data, of families with verified consent status.

Audit Outcomes at 5 years of age

 87%	Body mass index of children with a cleft had a healthy BMI. Children most likely to be of normal weight are those with CP, UCLP or BCLP.	 60%	Speech of children with a cleft affecting the palate had speech within the normal range. The proportion of children with 'normal' speech varied according to cleft type.
 62%	Dental health of children with a cleft had no decayed, missing or filled teeth (dmft=0), compared to 77% of their non-cleft peers.	 82%	Psychology of children with a cleft had 'Strengths and Difficulties' scores* in the low/normal range, compared to 90% of their non-cleft peers. Furthermore, 97% of families were screened at least once before the target age of 6.
 38%	Facial growth of children with a complete unilateral cleft lip and palate (UCLP) had scores reflecting good dental arch relationships.		

Research

Congenital malformations in children born with a cleft 39% of children had additional congenital malformations. These were most common in children with CP (53%), followed by BCLP (36%), UCLP (26%) and CL (22%). The circulatory, musculoskeletal and digestive systems were the most likely to be affected.	Congenital malformations of the circulatory system and speech at age 5  Children without malformations of the circulatory system were significantly more likely to have speech without difficulties than those with these malformations.	Differences in speech outcome between girls and boys at age 5 ? Females with a cleft palate +/- lip achieved significantly better speech outcomes than males at age 5. 
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For further information visit www.CRANE-Database.org.uk |  @CRANE_News

CRANE team



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Our Team



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Today's aims & objectives



Provide stakeholders with an opportunity to share views on the new outlier process - first experienced and reported on in 2021. Including:

- Barriers to data submission faced by cleft services with negative outlier status for some indicators, and
- learning lessons from services achieving positive outlier status
 - particularly for consent verification and outcome data completeness indicators.

Outlier policy

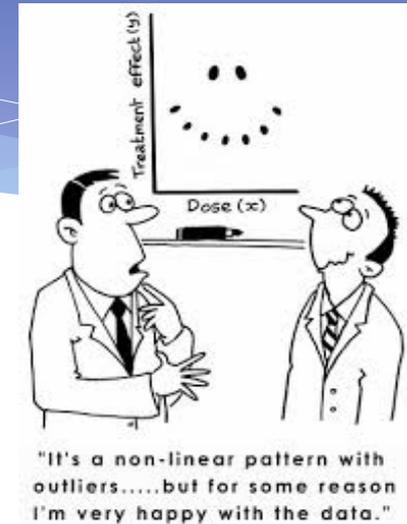


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- * Developed in-line with HQIP NCAPOP audits guidance
- * Piloted 2021
- * Introduce fully in 2022
 - * Outcomes 2012-14 births
- * Alert –
 - * 2 to 3 SD from national mean
- * Outlier
 - * $\geq 3SD$ in one reporting cycle
 - * if more than 2SD in 2 successive reports
- * Robust process with multiple check points / right of reply
- * In longer term integrity requires development of risk adjustment models



CRANE Data Entry System

For professionals For public News Contact us

RESOURCES REPORTS PUBLICATIONS ABOUT US

Home > Resources > CRANE Outlier Policy

CRANE Outlier Policy

Document describing the outlier policy for the Cleft Registry and Audit Network (CRANE)

This document sets out the process by which the performance of NHS cleft services in England, Wales and Northern Ireland - providing specialist support and clinical care to children born with cleft lip and/or palate and their families - will be assessed. As well as the process the CRANE Database Team will follow to manage any service that is found to fall outside the expected range of performance and therefore flagged as an outlier.

[Click here to download the CRANE Outlier Policy](#)


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Outlier process 2021

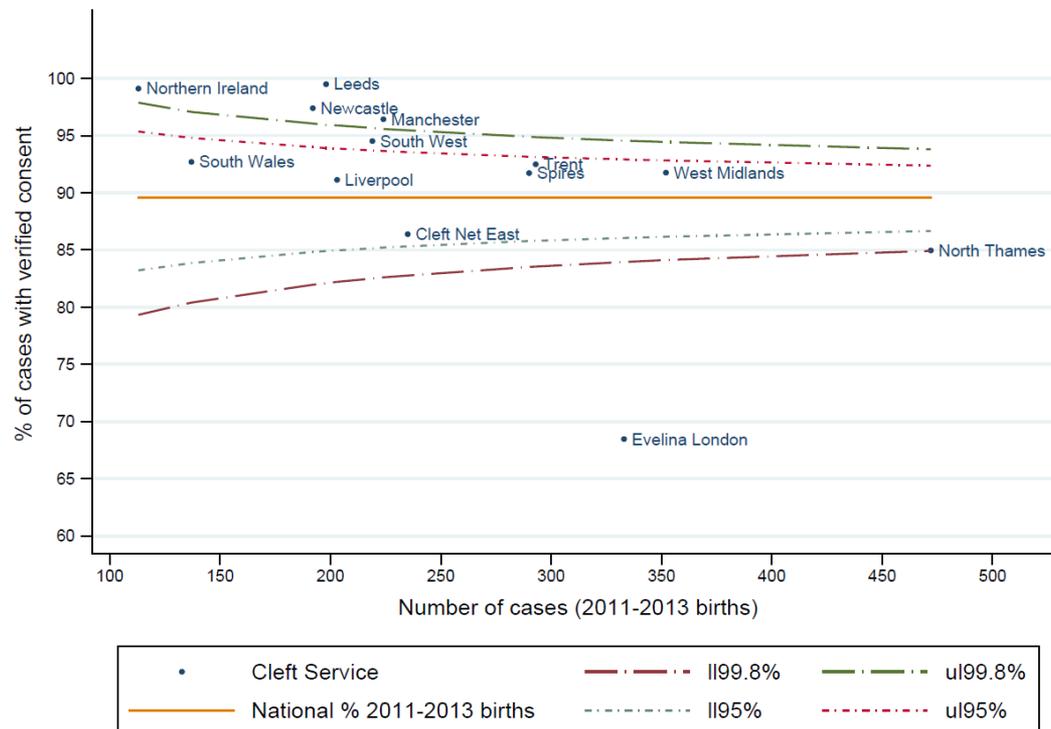


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Applied to 16 process and outcome indicators
- including consent = pivotal





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Today

Learning from good practice

Sharing learning and good practice



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Speakers – reflecting on the outlier process – include:

1. Peter Hodgkinson – on consent verification and outcome data completeness (Newcastle)
2. Dianne Phare – on consent verification (Manchester)
3. Jeanette Mooney – on facial growth outcome data completeness (Manchester)
4. Lorraine Britton – on speech outcome data completeness (Trent)
5. Vanessa Hammond – on psychology outcome data completeness (South Wales)
6. Jason Neil-Dwyer – on the process used to respond to the CRANE outlier process (Nottingham)



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Question and Answer session



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Recap and feedback

Recap of recent and upcoming CRANE developments



The capture of

- Syndromes and additional diagnoses – January 2021
- Ethnicity – March 2021
- Developmental Defects of Enamel (DDE) – February 2022

Key resources

- Guides – such as those supporting exports and transfers (by push pull)
- Videos

Becoming a UK-wide audit (including Scotland)

Next steps



- Data submission deadlines
 - Friday 25 February 2022 - Q3 2021/22 Dashboard
 - Friday 1 April 2022 - for preliminary report (previously known as audit day report)
- Use resources to help you check your data
- Contact crane@rcseng.ac.uk with queries
- Next session w/c 9 May 2022



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Thank you