Treble Cleft Quality Improvement Day
CRANE Update

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Clinical Research Fellow

18 November 2022

Overview

- Background

- Review of 2022 preliminary report

- Key quality improvement resources

CRANE Database

- Established in 2000

- England, Wales and Northern Ireland

- National Cleft Register (S251) and Outcomes Database (Consent)

- 15 Centralised Cleft Services submit data to CRANE

- Most recent Annual Report – December 2021

- Overseen by Cleft Development Group (parents, commissioners, clinicians)
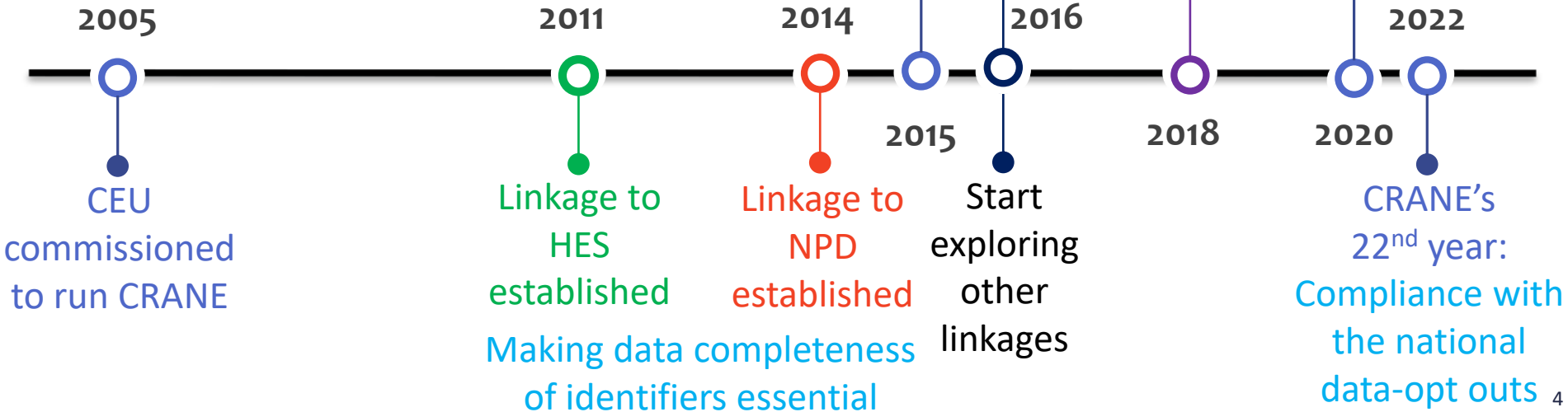
CRANE key timepoints

RCS System / IT support lost

CEU re-dev of Database & Website

GDPR enacted: Emphasizing importance of good IG

Northern Ireland officially joins

Website Re-dev

2005

2011

2014

2016

2022

2015

2018

2020

CEU commissioned to run CRANE

Linkage to HES established

Linkage to NPD established

Start exploring other linkages

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

Making data completeness of identifiers essential

2022 CRANE Timeline

CLEFT REGISTRY & AUDIT NETWORK

Cleft Registry and Audit NEtwork (CRANE) ANALYSIS TIMELINE 2022: Including dates for outlier process

The graphic below outlines the timeline that CRANE will work to in 2022.
Key data submission deadlines are also flagged – including those for the quarterly Specialised Services Quality Dashboards. For more information on the SSQD visit https://www.crane-database.org.uk/resources/dashboard-indicators-submitted-by-crane.
Patients recorded in CRANE up until the 31 December 2021 will be included in the 2022 preliminary report – used for preliminary identification of outliers – and included in the CRANE 2022 Annual Report.
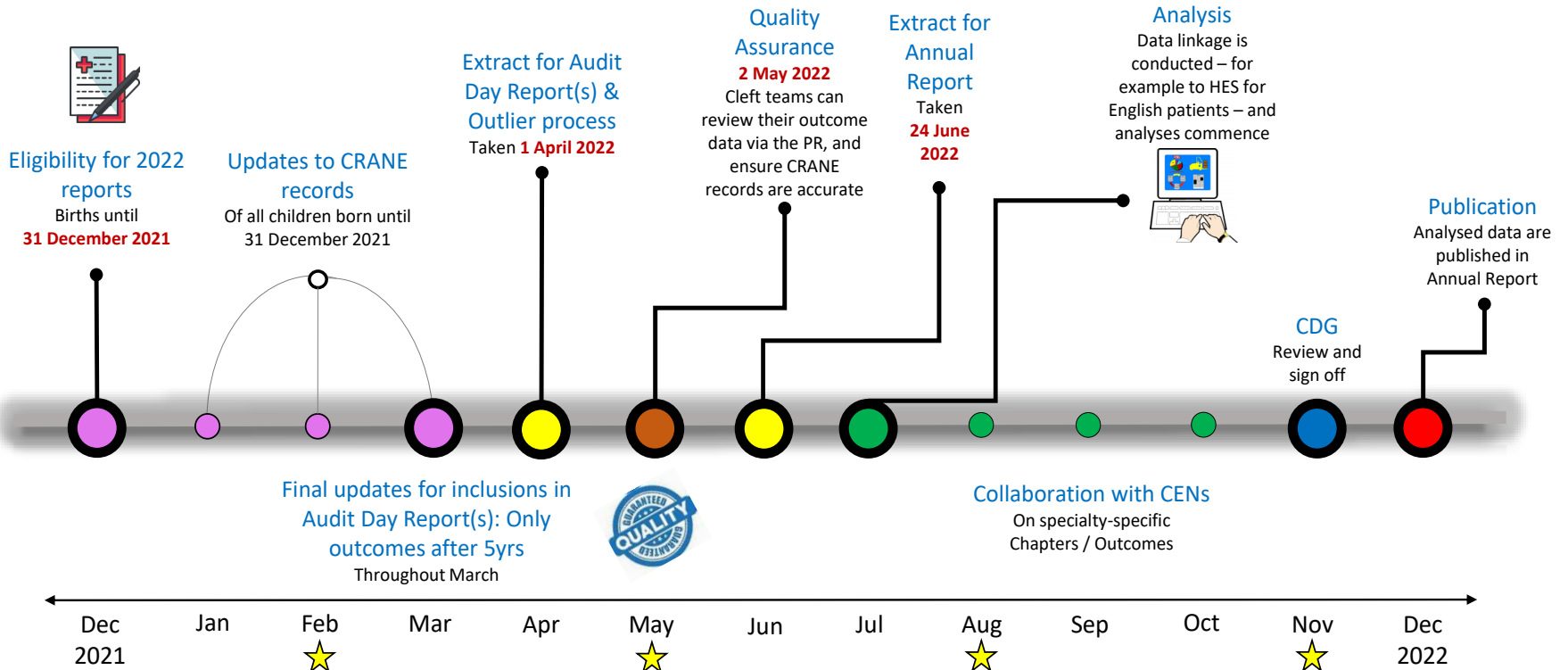Once the data for the CRANE 2022 Annual Report has been analysed, the reports will be written. The final draft then will be agreed by key stakeholders, including the CDG, before publication in December 2022.

Acronyms
PR: Preliminary Report
AR: Annual Report
CDG: Cleft Development Group
CEN: Clinical Excellence Network
QA: Quality Assurance

Key
- Updating records
- Extracts
- Dashboard
- Final updates for AR
- Analyses for AR
- CDG input
- Publication of Report

Eligibility for 2022 reports
Births until **31 December 2021**

Updates to CRANE records
Of all children born until 31 December 2021

Extract for Audit Day Report(s) & Outlier process
Taken **1 April 2022**

Quality Assurance
2 May 2022
Cleft teams can review their outcome data via the PR, and ensure CRANE records are accurate

Extract for Annual Report
Taken **24 June 2022**

Analysis
Data linkage is conducted – for example to HES for English patients – and analyses commence

Publication
Analysed data are published in Annual Report

CDG
Review and sign off

Final updates for inclusions in Audit Day Report(s): Only outcomes after 5yrs
Throughout March

Collaboration with CENs
On specialty-specific Chapters / Outcomes

Dec 2021 | Jan | Feb ⭐ | Mar | Apr | May ⭐ | Jun | Jul | Aug ⭐ | Sep | Oct | Nov ⭐ | Dec 2022

Review of 2022 preliminary report

Registry chapters → Consent chapter → Outcome chapters

Registry chapters

- Collected without consent
- Engagement with these chapters is particularly important to funders
- In general it is completed well by your services
- Few areas for potential improvement
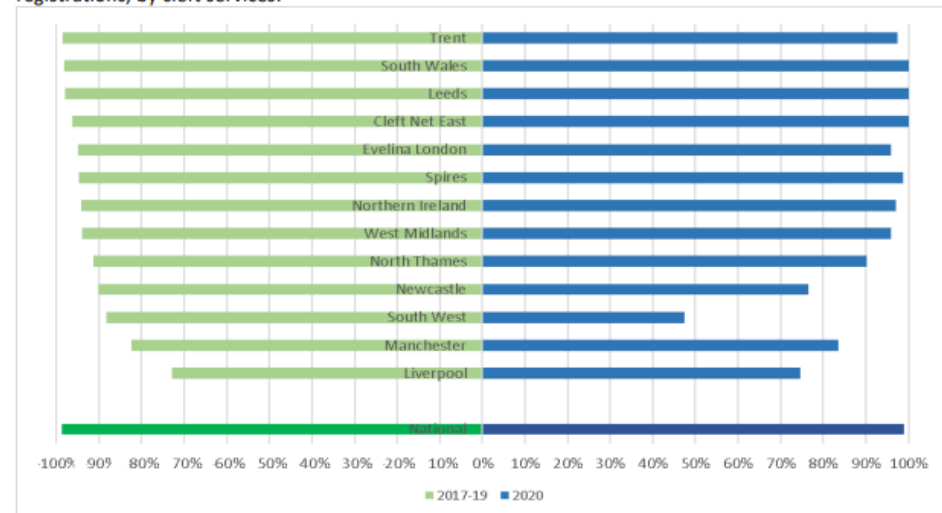
Registry chapters

- Most services good at recording sex of child

- Most services good at recording cleft type but South West below average

- Potential area for improvement

Figure 3.3. Percentage of children with cleft type specified in 2017-19, compared to national average for 2020 registrations, by cleft services.

Note: Children registered in the CRANE Database between 1st January 2017 and 31st December 2020, by the 30 June 2021.

Registry chapters

- Combined data for 2017-19 very good

- 2020 data for Spires shows drop in diagnosis antenatally and at birth

Figure 3.4. Percentage of timely diagnoses, including those made antenatally and at birth, among all CRANE-registered children, born 2017-19, according to cleft service – by comparison with children born 2020.
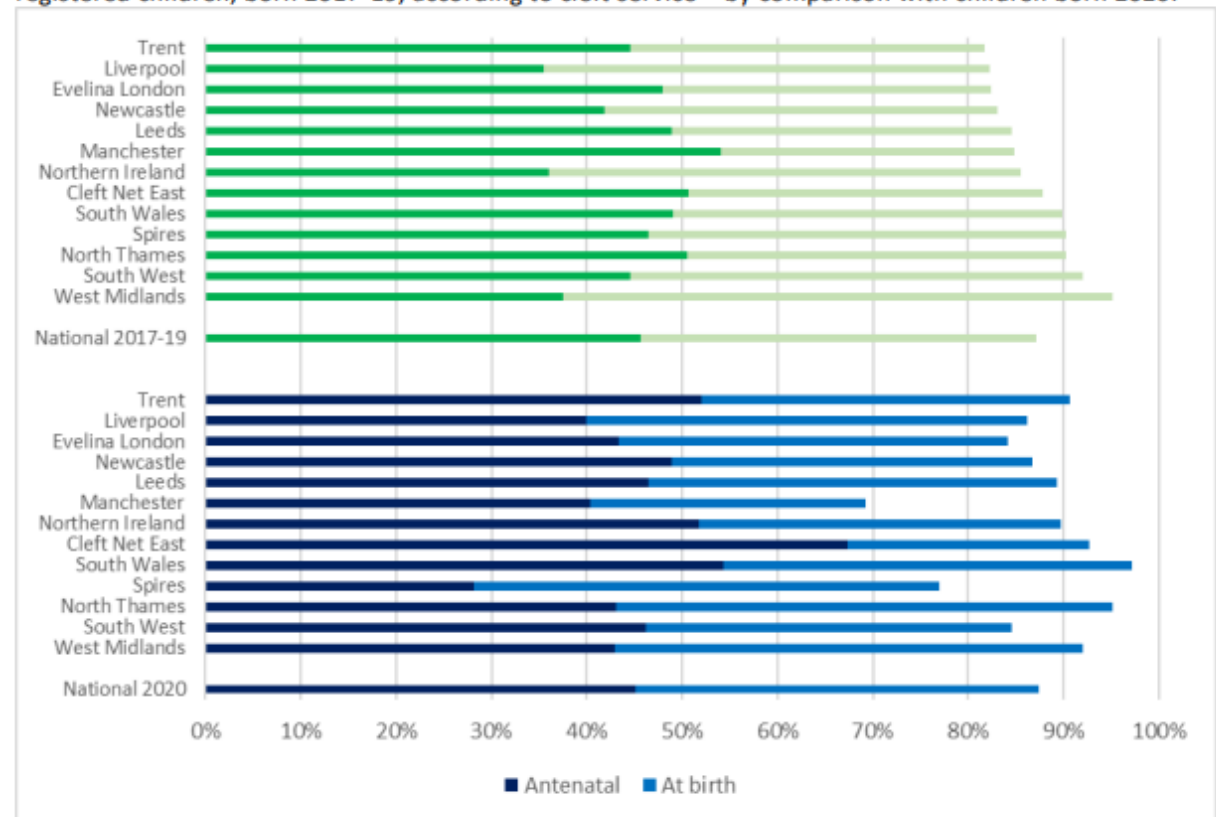
Note: Children missing diagnosis time are excluded. Includes unspecified cleft types.

Registry chapters

CLEFT REGISTRY & AUDIT NETWORK

Table 3.1. Number (%) of CRANE-registered children born between 2017 and 2019 with a cleft palate, according to the timing of diagnosis and region / unit.

Cleft service	Antenatal	At birth	< 72 hours		≤1 week	≤1 month	≤6 months	>6 months	All
Newcastle	1 1.7%	41 70.7%	2	3.4%	5 8.6%	3 5.2%	6 10.3%	0 0%	58
Leeds	1 1.3%	53 69.7%	9	11.8%	7 9.2%	2 2.6%	4 5.3%	0 0%	76
Liverpool	1 1.4%	48 67.6%	15	21.1%	2 2.8%	4 5.6%	1 1.4%	0 0%	71
Manchester	0 0.0%	48 68.6%	9	12.9%	6 8.6%	5 7.1%	1 1.4%	1 1.4%	70
Trent	1 0.8%	81 64.8%	16	12.8%	10 8%	4 3.2%	9 7.2%	4 3.2%	125
West Midlands	1 0.7%	123 89.1%	4	2.9%	4 2.9%	5 3.6%	1 0.7%	0 0%	138
Cleft Net East	0 0.0%	59 72%	12	14.6%	6 7.3%	3 3.7%	2 2.4%	0 0%	82
North Thames	9 6.0%	110 73.3%	9	6%	8 5.3%	4 2.7%	10 6.7%	0 0%	150
Spires	2 2.1%	73 76.8%	9	9.5%	2 2.1%	4 4.2%	3 3.2%	2 2.1%	95
South Wales	1 2.0%	43 84.3%	3	5.9%	0 0%	2 3.9%	2 3.9%	0 0%	51
South West	6 8.1%	57 77%	5	6.8%	4 5.4%	2 2.7%	0 0%	0 0%	74
Evelina London	6 4.0%	92 61.3%	24	16%	10 6.7%	11 7.3%	6 4%	1 0.7%	150
Northern Ireland	0 0.0%	32 69.6%	5	10.9%	1 2.2%	4 8.7%	0 0%	4 8.7%	46
All	**29 2.4%**	**860 72.5%**	**122**	**10.3%**	**65 5.5%**	**53 4.5%**	**45 3.8%**	**12 1%**	**1,186**

Note: Recording of 'timing of diagnosis' within 72 hours commenced in May 2014 to align CRANE data collection with NIPE standards[19].
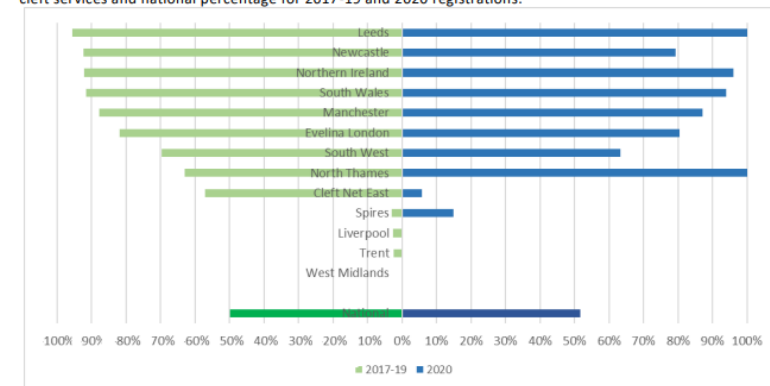
Registry chapters

- West midlands and Spires poor at recording gestational age and birth weight

Figure 3.7. Percentage of CRANE-consented children with recorded gestational age in 2017-19 and 2020, by cleft services and national percentage for 2017-19 and 2020 registrations.

Note: Al children registered in CRANE between 01 January 2017 and 31 December 2020, by the 30 June 2021. Children without consent for data collection at birth are excluded. West Midlands cleft service submitted no gestational age data between 2017 and 2020.

Figure 3.8. Percentage of CRANE-consented children with recorded birth weight in 2017-19 and 2020, by cleft services and national percentage for 2017-19 and 2020 registrations.
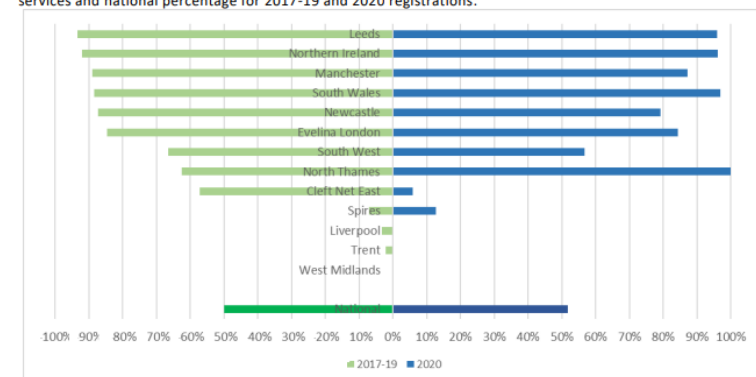
Note: All children registered in CRANE between 01 January 2017 and 31 December 2020, by the 30 June 2021. Children without consent for data collection at birth are excluded. West Midlands cleft service submitted no birth weight data between 2017 and 2020.
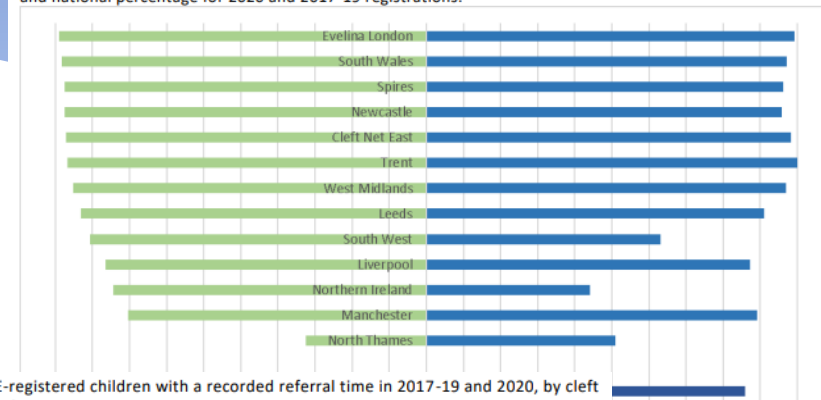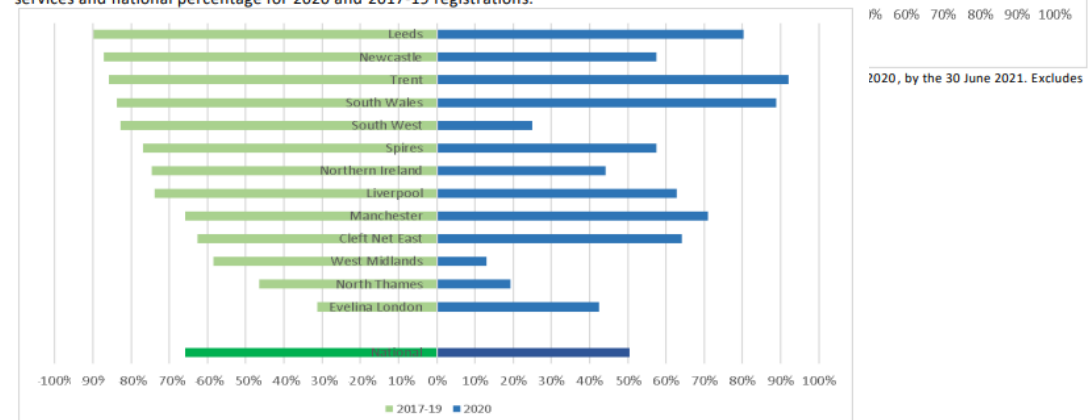
Registry chapters

- All good at recording contact time – slight drop for South West in 2020 data

- Referral time not recorded quite as well overall – South West and West Midlands drop in 2020 data

Figure 3.10. Percentage of CRANE-registered children with a recorded contact time in 2020, by cleft services and national percentage for 2020 and 2017-19 registrations.

Figure 3.9. Percentage of CRANE-registered children with a recorded referral time in 2017-19 and 2020, by cleft services and national percentage for 2020 and 2017-19 registrations.

■ 2017-19 ■ 2020

Note: All children registered in CRANE between 01 January 2017 and 31 December 2020, by the 30 June 2021. Excludes children who died within the first week after birth.

Consent chapter

- Important for the outlier policy

- Important for outcome reporting within each discipline

Outlier policy

- Developed in-line with HQIP guidance with CDG support
- 2012-2014 Birth cohort first year (last year pilot)
- Alert if between 2 and 3 SD from national mean
- Outlier if more that 3SD from national mean in one reporting cycle or if more than 2SD (alert) in 2 successive reports

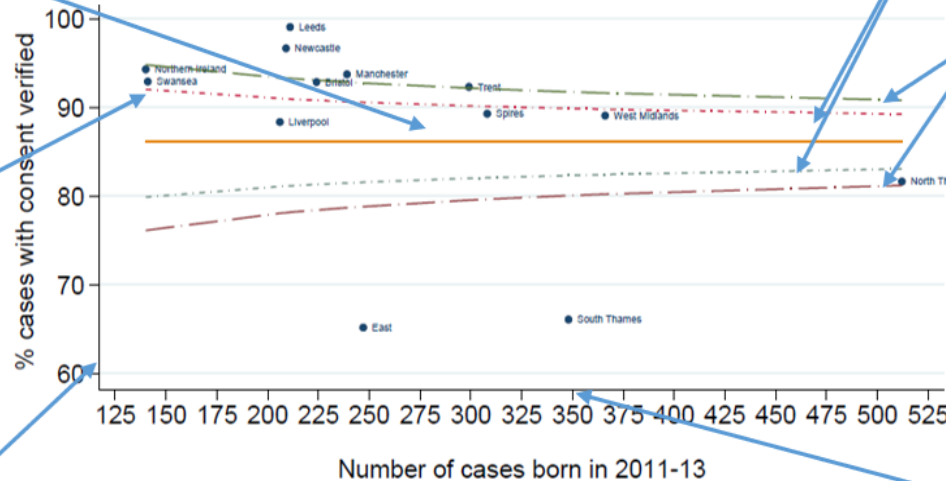- Integrity requires development of risk adjustment models

Funnel plots

- The overall national percentage is shown as a horizontal line through the centre of the graph

- Each point on the funnel plot represents a region / unit

- Each funnel plot is for one outcome, with its values shown on the vertical/Y axis

- The graph shows two funnels that lie on either side of the benchmark and are called the control limits – similar to confidence intervals – that fall either side of the overall percentage

- Inner lines show two standard deviations or 95% control limits

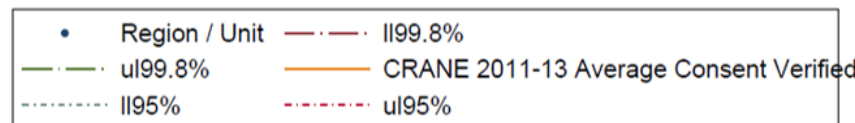- Outer lines represent three standard deviations or 99.8% control limits

- The funnel shape is formed because the control limits get narrower as the total number of patients in an organisation increases

- The size of the teams' cohort is shown on the horizontal or X axis

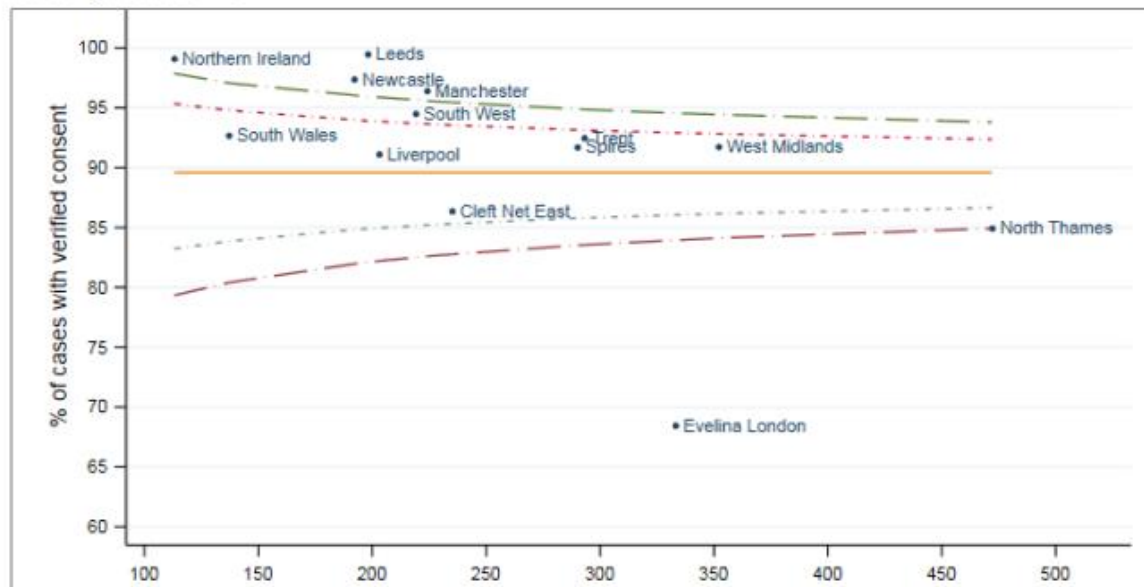# Consent chapter

- All above average for verified consent

Figure 3.11. Funnel plot showing the percentage of CRANE-registered children (born 2011-2013) with verified consent, according to cleft service.

Outcome chapters - Child growth

- Low completion rate nationally
- South West and West Midlands negative outliers
- South Wales positive outlier
- Spires above average
- All in range for healthy BMI funnels

Figure 4.1 Funnel plot showing the percentage of CRANE-consented 5-year olds, born 2011-2013, with recorded child growth data submitted to CRANE, according to cleft service.
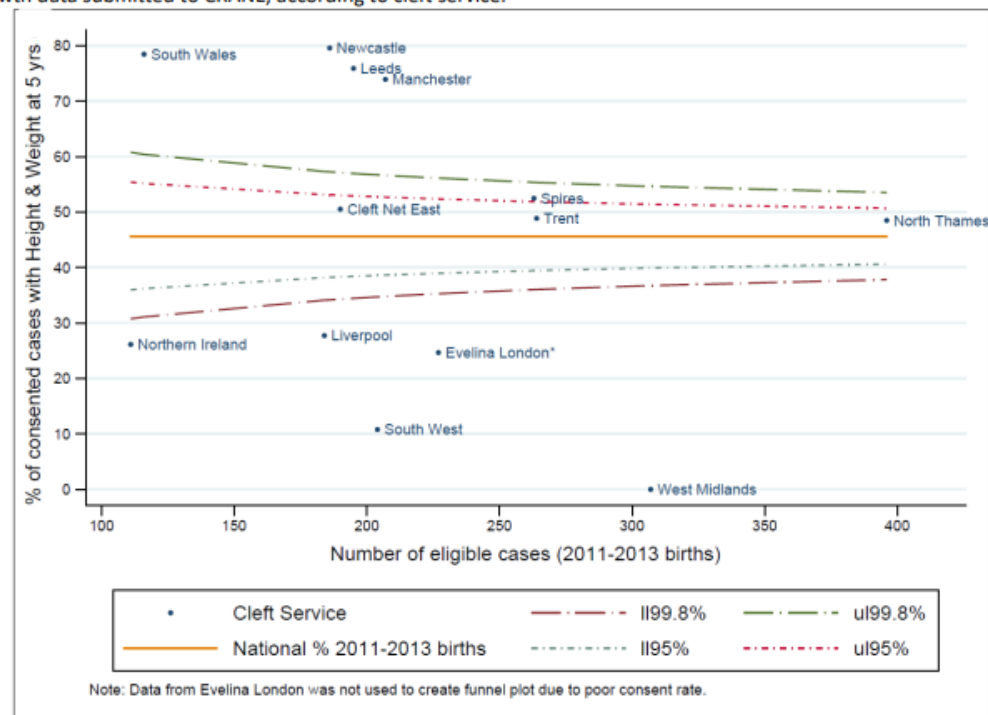
Note: Data from Evelina London was not used to create funnel plot due to poor consent rate.

Note: Registered in CRANE by 30 June 2021. Funnel plot centred on the adjusted national percentage (45.6%) of children (born 2011-2013) with growth outcomes at the age of five years reported. See Appendix 8 for the raw data (and exclusions) used to create this funnel plot.

Outcome chapters – Dental

- South west negative outlier for data completeness
- Others all positive outliers
- West midlands and Spires just below 95% for dmft>0 (positive outcome)
- Spires negative outlier for dmft>5 (positive outcome)

Figure 4.4. Funnel plot showing the percentage of CRANE-consented 5-year olds, born 2011-2013, who had dmft data submitted to CRANE, according to cleft service.
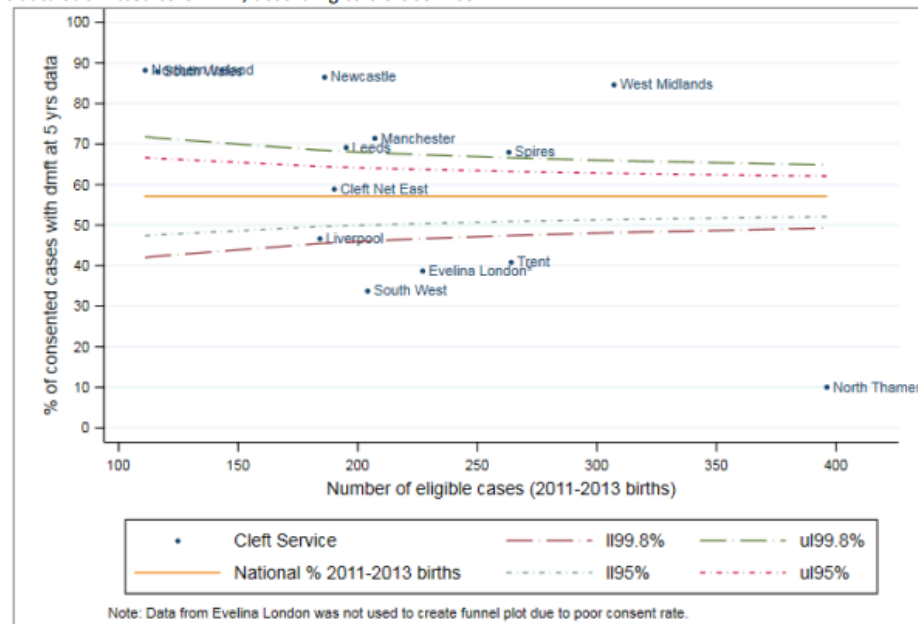
Note: Data from Evelina London was not used to create funnel plot due to poor consent rate.
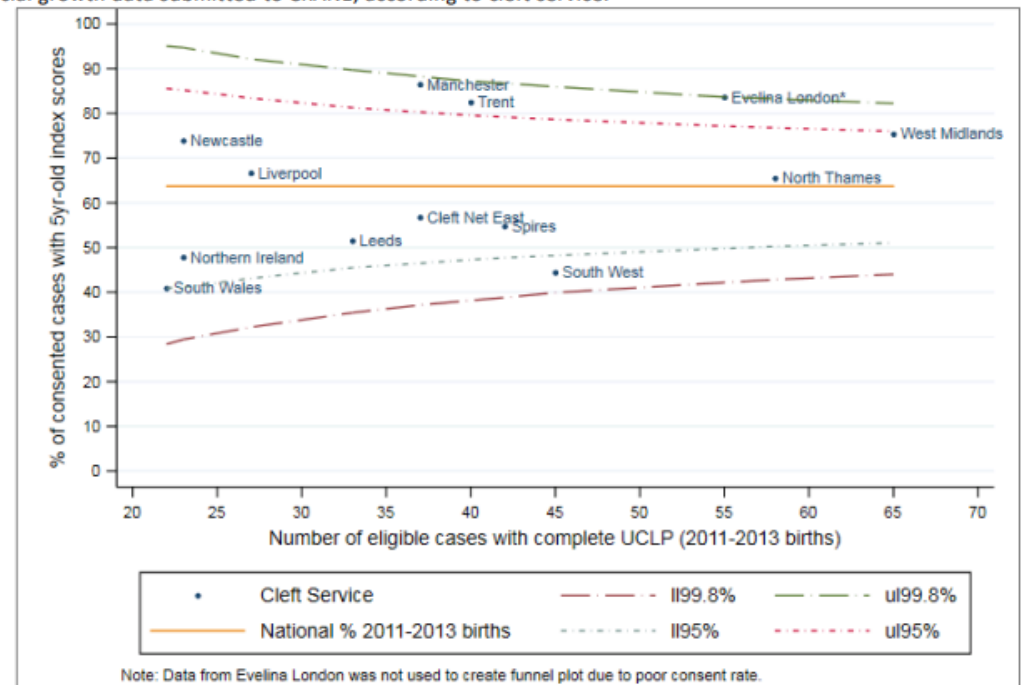
Note: Registered in CRANE by 30 June 2021. Funnel plot centred on the adjusted national percentage (57.1%) of children (born 2011-2013) with dmft data reported. See Appendix 9 for the raw data (and exclusions) used to create this funnel plot.

Outcome chapters – Facial growth

- South west just below 95% for data completeness
- Less than 20% nationally had data for 2014 (>60% for 2011-13)
- Good facial growth – all within funnel

Figure 4.8. Funnel plot showing the percentage of CRANE-consented 5-year olds, born 2011-2013, who had facial growth data submitted to CRANE, according to cleft service.

Note: Data from Evelina London was not used to create funnel plot due to poor consent rate.

Note: Registered in CRANE by 30 June 2021. Funnel plot centred on the adjusted national percentage (63.7%) of children (born 2011-2013) with facial growth outcomes at the age of five years reported. See **Appendix 10** for the raw data (and exclusions) used to create this funnel plot.
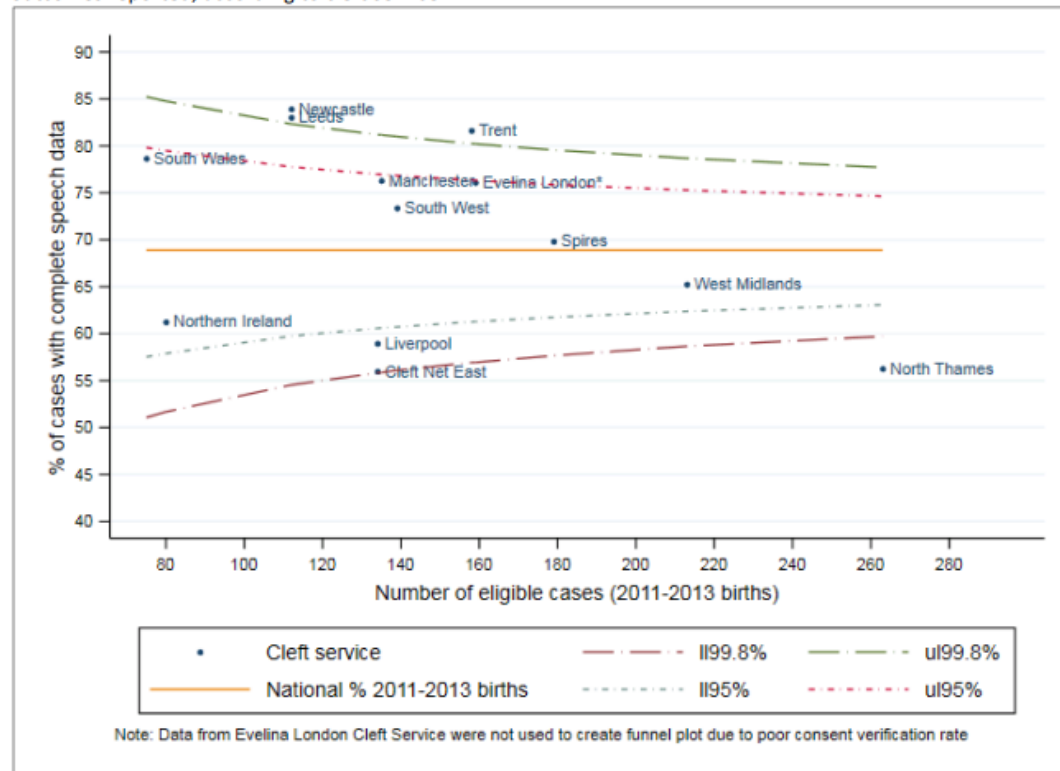
Outcome chapters – Speech

- All within funnel for data completeness

- Speech within normal range (SS1)– all within funnel

- SS2a – all within funnel

- SS3 – all within funnel

Figure 4.11. Funnel plot showing the percentage of CRANE-consented 5-year olds, born 2011-2013, with speech outcomes reported, according to cleft service.

Note: Data from Evelina London Cleft Service were not used to create funnel plot due to poor consent verification rate

Note: Registered in CRANE by 30 June 2021. Funnel plot centred on the adjusted national percentage (68.9%) of children (born 2011-2013) with speech outcomes reported. See Appendix 11 for the raw data (and exclusions) used to create this funnel plot.

Outcome chapters – Psychology

- South Wales positive outlier for data completeness
- All rest within funnel (Sp/SW upper end)
- Drop for West Midlands 2014 data
- Spires/West Midlands negative outliers for screen before age 6
- West Midlands close to being outlier for TIM score of 1a+ and negative outlier for high/very high SDQ scores

Figure 4.16. Funnel plot showing the percentage of CRANE-consented 5-year olds, born 2011-2013, who had all psychology 5-year-audit data submitted to CRANE, according to cleft service.
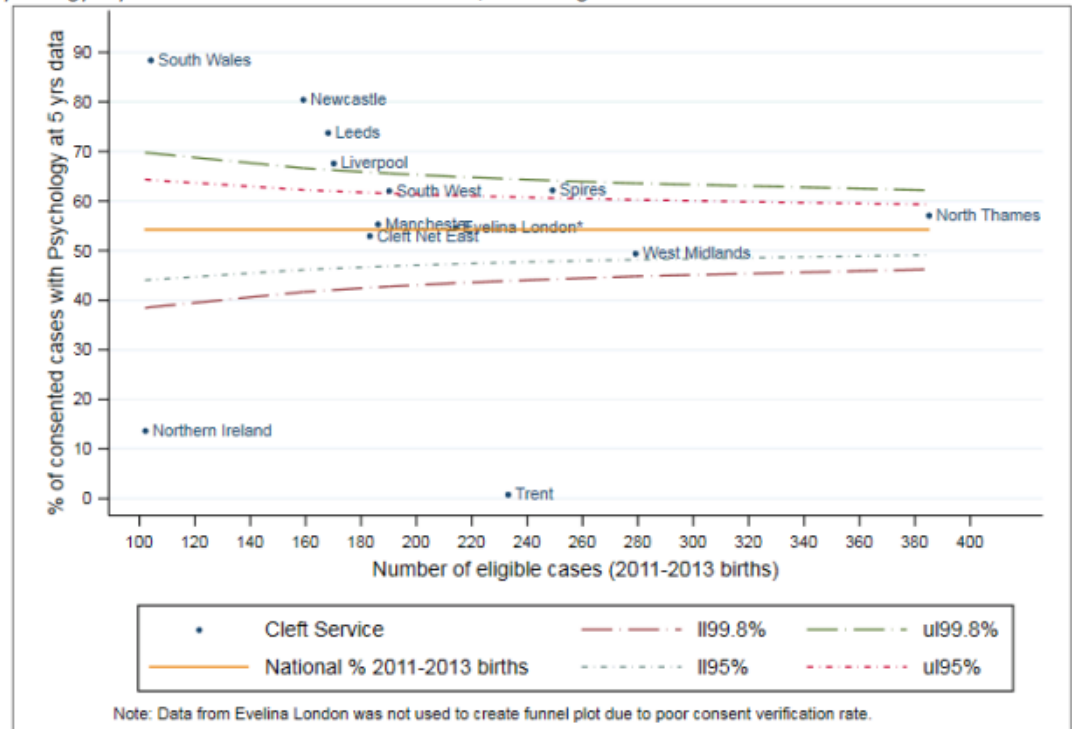
Note: Data from Evelina London was not used to create funnel plot due to poor consent verification rate.

Note: Registered in CRANE by 30 June 2021. Funnel plot centred on the adjusted national percentage (54.2%) of children (born 2011-2013) with psychology outcomes reported. See Appendix 12 for the raw data (and exclusions) used to create this funnel plot.

Quality Improvement Resources

- Data Dictionary

- Database guides and video demonstrations

- Data collection sheets

- Local action plan

- Excel workbooks to flag missing data

Data Dictionary

CRANE-Database-Data-Dictionar × +

crane-database.org.uk/content/uploads/2022/07/CRANE-Database-Data-Dictionary-July-2022.pdf

The Eagle homepage   HES Analysis Portal...   Buffer   CRANE - The Cleft...   Venngage   Notifications / Twitt...   Cleft Lip & Palate A...   ARAMIS - NIHR Aca...

CRANE-Database-Data-Dictionary-July-2022.pdf   1 / 10   —   146%   +   ⊡ ◇

CRANE Database - Data Dictionary: July 2022

KEY: * 'Notification only' data items / fields I.e. Patient consent = No/DK. ** 'Patient registration short' Export fields. ¥ Data items / fields tha

Section / Data item	Field name	Response values / labels	Description These descriptions are available through information (i) buttons found next to each data item.	Guidance & Notes
Patient Registration				
Patient Consent				
Consent status*	consent**	1 = No 2 = Yes 3 = Unknown, awaiting verification 4 = Not possible to verify	As indicated on consent form.	* Notification fields I.e. Should always be complete patient consent = No (1) / DK (3) / Not verified (4)
Consent status: Please give further details	consent_details	Text	Reason why if choose 3 or 4 for 'consent'. "*Please give further details:" (Field name: consent_details).	
Linkage of CRANE data to Health data*	consent_health	1 = No 2 = Yes 3 = Unknown, awaiting verification 4 = Not possible to verify 5 = Registered prior to new 2016 system (only visible to Admin)	As indicated on consent form. This field may also capture future requests to NOT link patient's CRANE data to Health data.	* Notification fields I.e. Should always be complete patient consent = No (1) / DK (3) / Not verified (4)
Linkage of CRANE data to Education data*	consent_education	1 = No 2 = Yes 3 = Unknown, awaiting verification 4 = Not possible to verify 5 = Registered prior to new 2016 system (only visible to Admin)	As indicated on consent form. This field may also capture future requests to NOT link patient's CRANE data to Education data.	* Notification fields I.e. Should always be complete patient consent = No (1) / DK (3) / Not verified (4)
Cleft team details				
			Administrative unit name. More than one unit name may be available for selection from a	

Data collection forms

Database guides and video demonstrations

Resources

Filter resources
- ☐ Professional
- ☐ Public

Filter by type
- ☐ Infographics
- ☐ Data
- ☐ Guidance
- ☐ Guidance - Videos
- ☐ Quality Improvement
- ☐ Templates & Proformas
- ☐ Governance
- ☐ Policies

Submit

Reset filter

Posted 12 August 2022 in **Guidance**, and **Guidance - Videos**.
Video demonstration: Identifying cases missing speech data at five years of age

Posted 31 March 2022 in **Guidance**, and **Guidance - Videos**.
Video demonstration: Identifying cases missing psychology data at five years of age

Posted 31 March 2022 in **Data**, **Guidance**, and **Guidance - Videos**.
Video demonstration: Managing Patient Transfers

Posted 28 February 2022 in **Data**, **Guidance**, and **Guidance - Videos**.
Video demonstration: Recording syndromes and additional diagnoses

Local action plan

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 11	**Child growth at 5 years** 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] Indicator: #6	*Suggested actions:* *Does your team have a protocol for how these outcome data are systematically collected, recorded and documented on CRANE Database?* *Has a specific individual been assigned responsibility to ensure collection / submission of these data points?* *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).* *Does this reflect what happens in your organisation? If not, what steps can you take to improve assessment of these outcomes? What action needs to be taken?* *Where collection / submission low assigned individual should reach out to cleft services with high data completeness and share learning loacally, champion introduction of similar processes applicable to the local healthcare environment* *[Consider incorporating virtual MDT meeting where all audit data is reviewed on CRANE to ensure that whole team happy with record]*				

Excel workbooks

- ## Workbooks sent out March 2022

Cleft service	Postcode n	LAHSAL n	DMFT n	Current patient n	Total
West Midlands	0	53	42	20	115
Spires	2	83	184	52	321
South West	1	49	8	6	64
South Wales	1	56	5	5	67

What next??

- Report went to CDG 10th Nov

- Planned publication 9th Dec

- Making It Better Session (MDT team) – 30th Jan

- Data Q and A quarterly session – 28th Feb

- Preliminary report – 1st April

Thank you
Any Questions?