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CRANE 2023 Making it better session



30 Jan 2023

S Butterworth, C Russell, J Medina & K Fitzsimons

On behalf of the CRANE Database team



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Welcome and Introductions

No recordings please



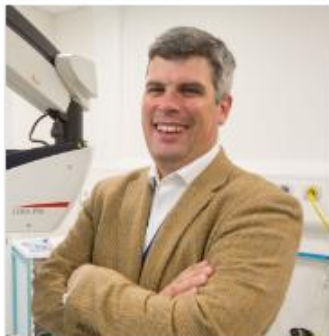
CRANE team



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Aims



Provide stakeholders with an opportunity to share views / reflect on the CRANE Annual Report 2022.

- Answer questions in advance of the submission deadline for the 2023 Preliminary Report.
- Identify barriers to data submission faced by services with negative outlier status.
- Share lessons learnt from services with positive outlier status.
- Updates and key Database developments.

CRANE Annual Report 2022



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- Data entered by 27 June 2022 included
- Figures presented - calculated using valid data as denominators
- Subject to the usual inclusions and exclusions

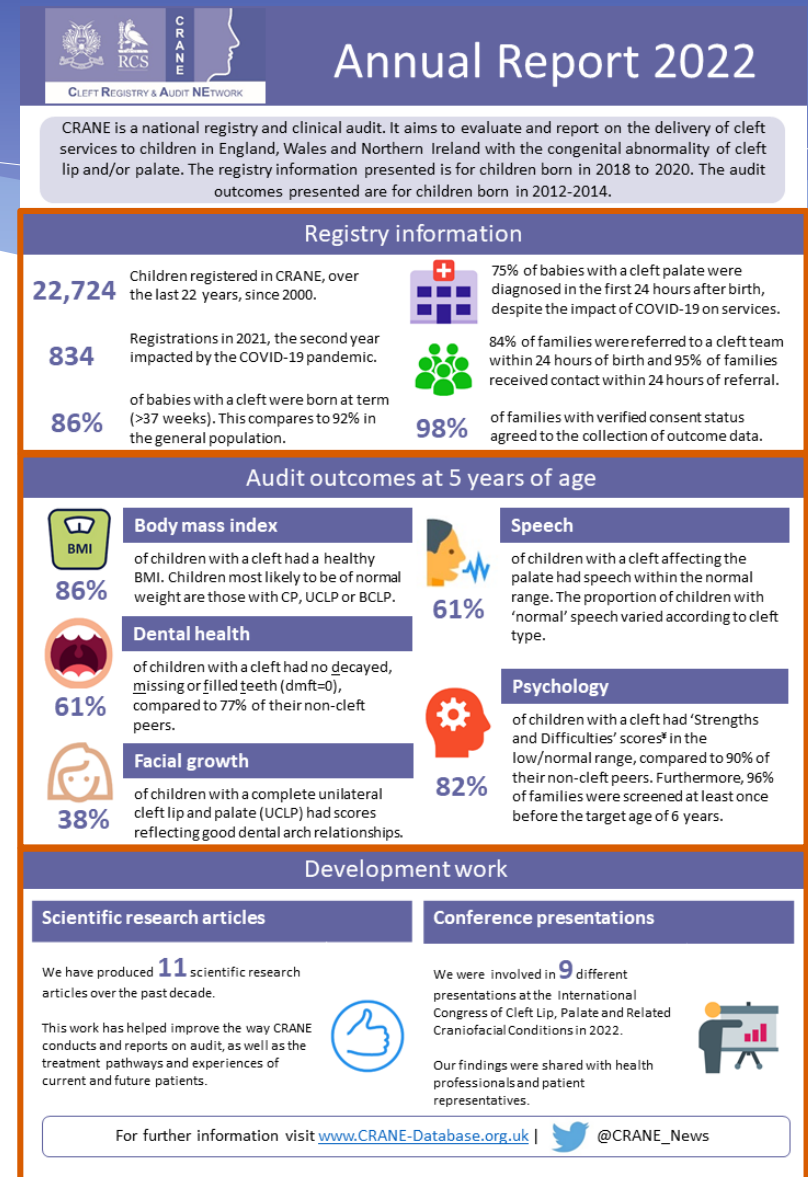
Cohort summary	Data source	The CRANE Database (consented cases only)
	Birth years	Three years: 2012 to 2014. Plus summary information on 2015 births ³⁰
	Denominator	1,285 Children with a recorded height and weight at 5 years
	Numerator	Number of children in each body mass index (BMI) category (underweight, healthy weight, overweight and obese)
	Exclusions	<ul style="list-style-type: none">• Children without consent to data collection• Children who died before the age of 5 years• Children with submucous cleft palates³¹• Children without recorded height and weight at the age of 5

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Evaluation and reporting on the delivery of cleft services.

Reporting on:

- Registry information
- Audit outcomes
- Development work from research



Supplementary tables - new layout for 2022



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Royal College of Surgeons of England
ADVANCING SURGICAL CARE

CRANE Audit Report 2022 - Supplementary tables and information

Table Of Contents (TOC)

Chapter	Birth year(s)	Topic
Registration	2018-20 combined and 2021	
Chapter 3.1		Registrations in CRANE 3.1.1. Registrations 3.1.3. Sex and Cleft type
Chapter 3.2		Timing of diagnosis 3.2.2. Timing of diagnosis for all cleft types 3.2.3. Timing of diagnosis for clefts involving the lip
Chapter 3.3		Timely diagnosis of cleft palate 3.3. Timely diagnosis of cleft palate
Chapter 3.4		Gestational age and birth weight 3.4.2. Gestational age 3.4.4. Birth weight
Chapter 3.5		Contact with cleft services 3.5.2. Referral time and contact time
Consent status	2012-14 combined and 2015	
Chapter 4.1		4.1. Consent

Provided in a workbook alongside the Annual Report

Consent - 2012-2014 births

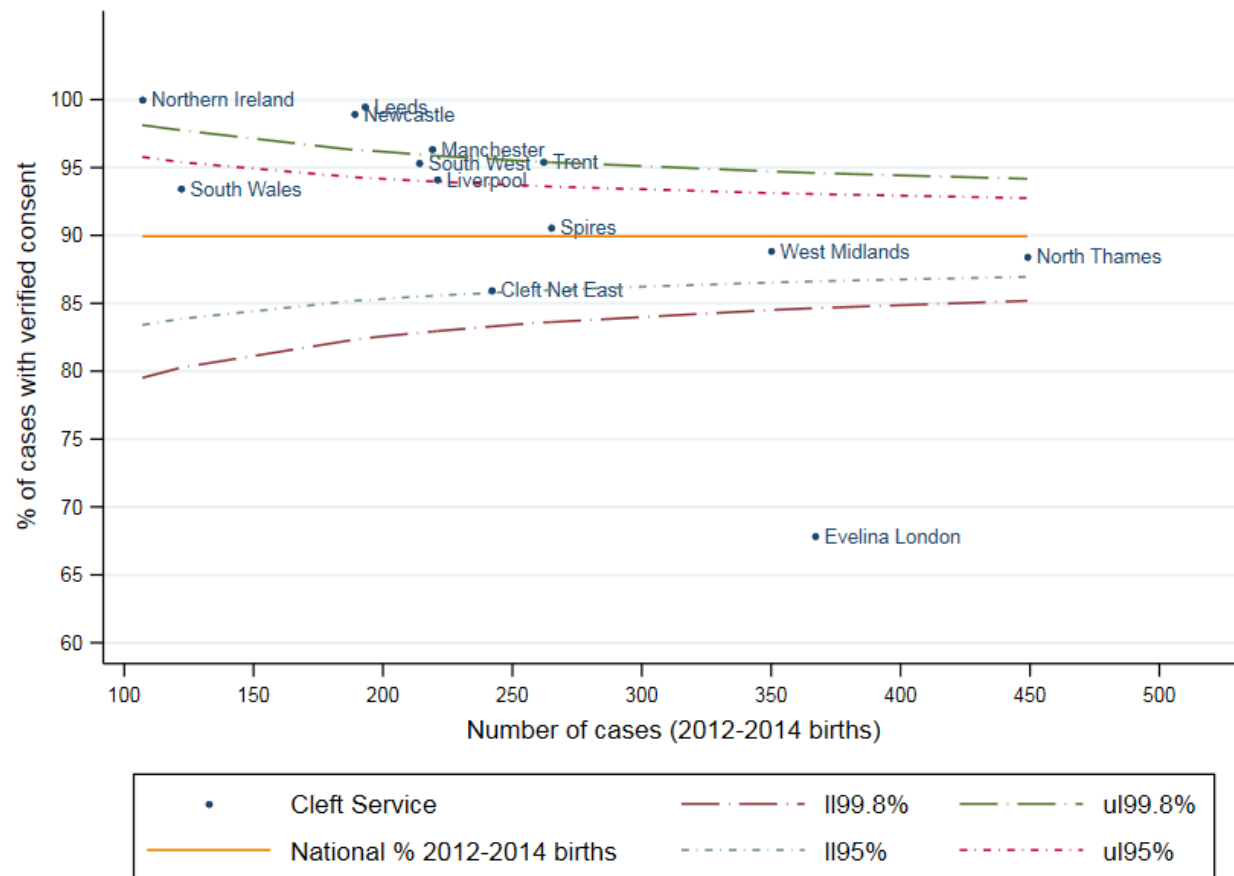


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- Positive outliers remain the same
- Evelina London negative outlier



Child growth completeness - 2012-2014 births

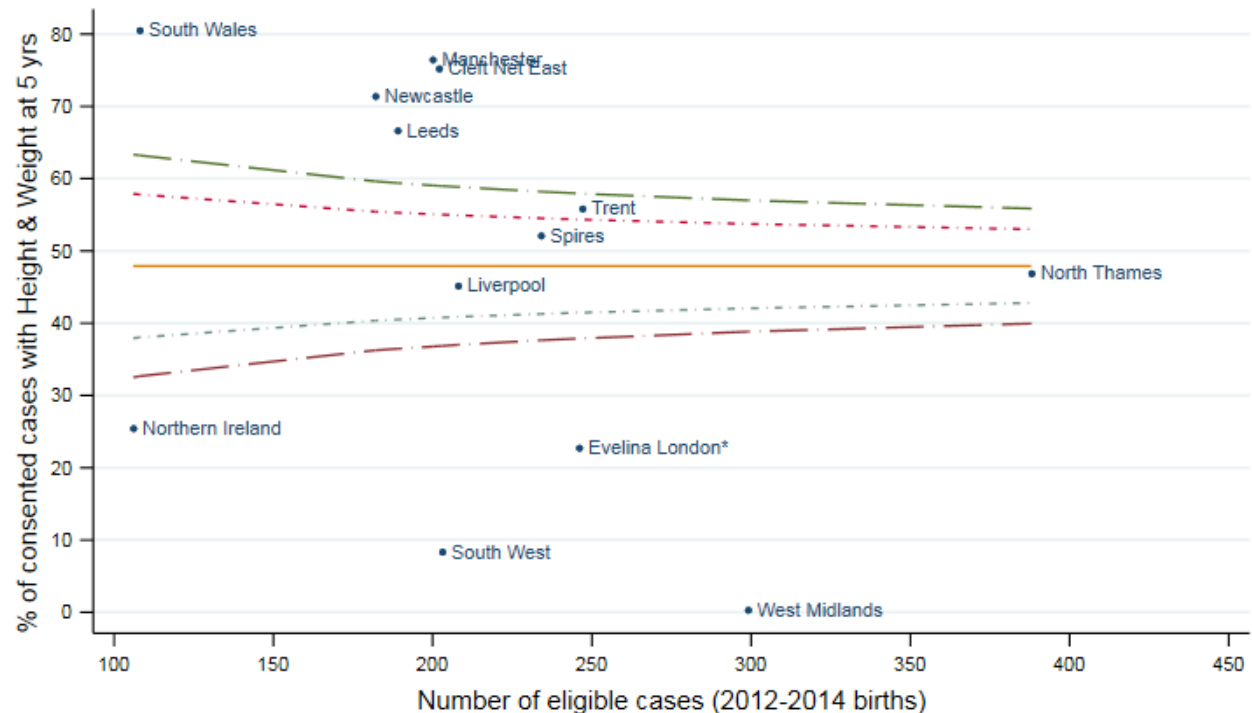


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- Average just under 50%
- Cleft Net East additional +ve outlier
- Liverpool no longer -ve outlier



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

Healthy BMI - 2012-2014 births

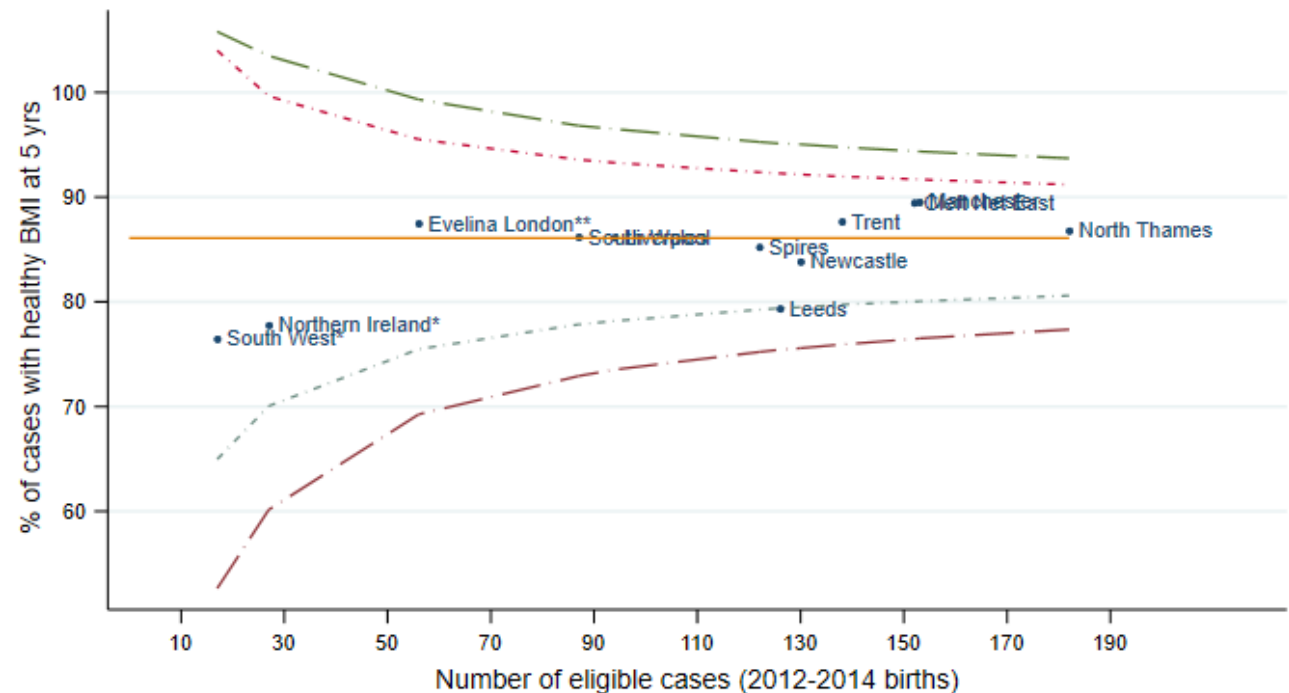


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- All remain within funnel



Note 1: Data from Evelina London was not used to create funnel plot due to poor consent verification rate.
 Note 2: Data from Liverpool, West Mids, S West, Evelina & N.I. not used to create funnel plot due to poor data completion rates.
 Note 3: West Midlands had one recorded patient with Height & Weight (BMI) data.

Dental health completeness – 2012-2014 births

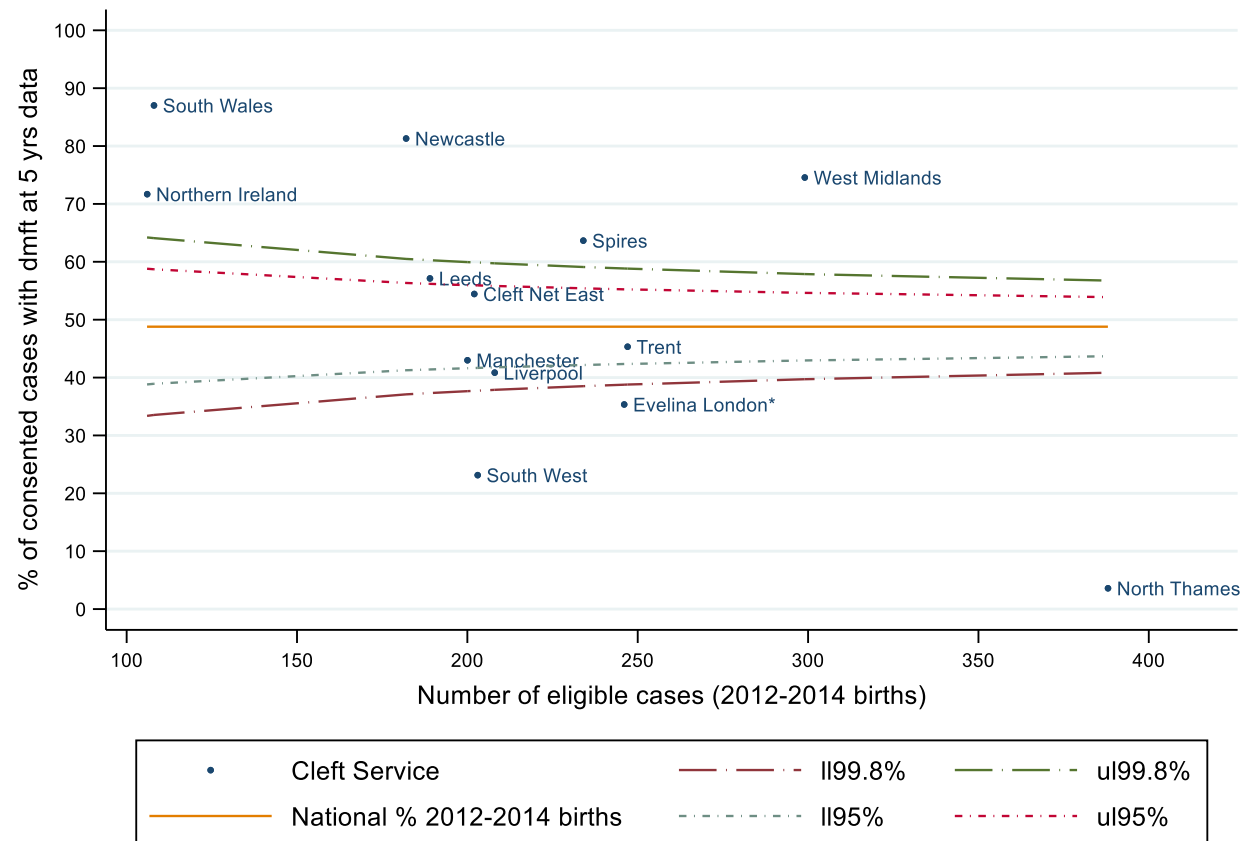


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- National average drop 9%
- Trent no longer –ve outlier
- Leeds and Manchester no longer +ve outliers
- North Thames negative outlier



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

dmft >0 – 2012-2014 births

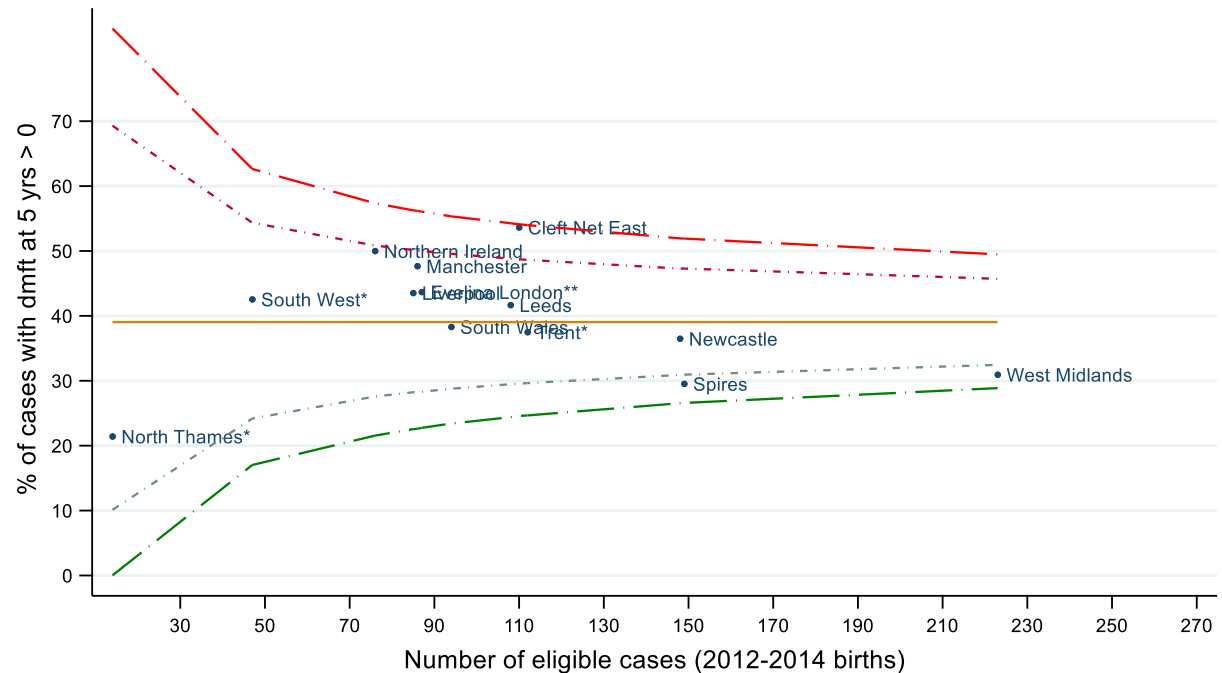


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- Small national average increase
- Overall volume drop ~250
- Cleft Net East at risk of - ve outlier



Note 1: Data from Evelina London was not used to create funnel plot due to poor consent verification rate.
 Note 2: Data from N Thames, S West & Evelina were not used to create funnel plot due to poor data completion rates.

dmft >5 - 2012-2014 births

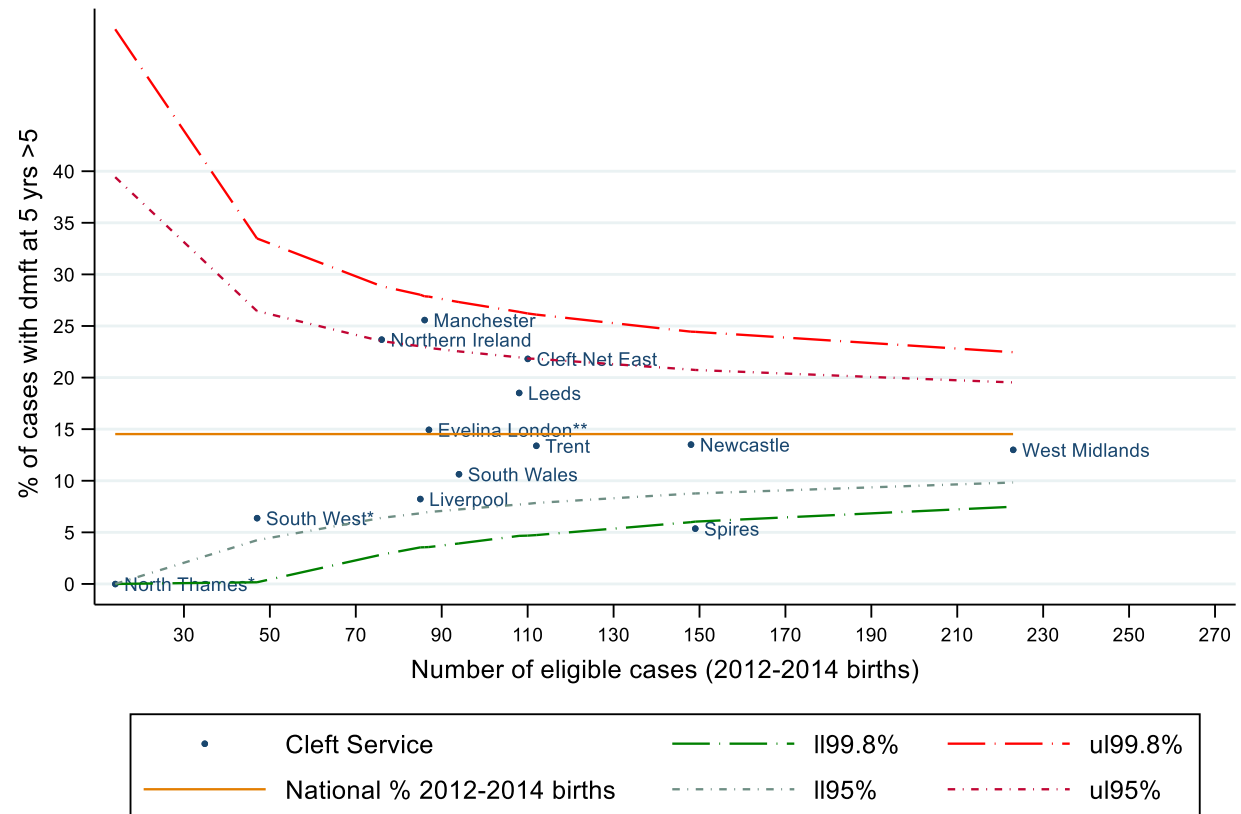


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- Overall volume drop ~250
- Spires still +ve outlier
- Manchester no longer -ve outlier
- NI -ve alert (CleftNetEast close)



Note 1: Data from Evelina London was not used to create funnel plot due to poor consent verification rate.

Note 2: Data from N Thames, S West & Evelina were not used to create funnel plot due to poor data completion rates.

5YI data completeness - 2012-2014 births

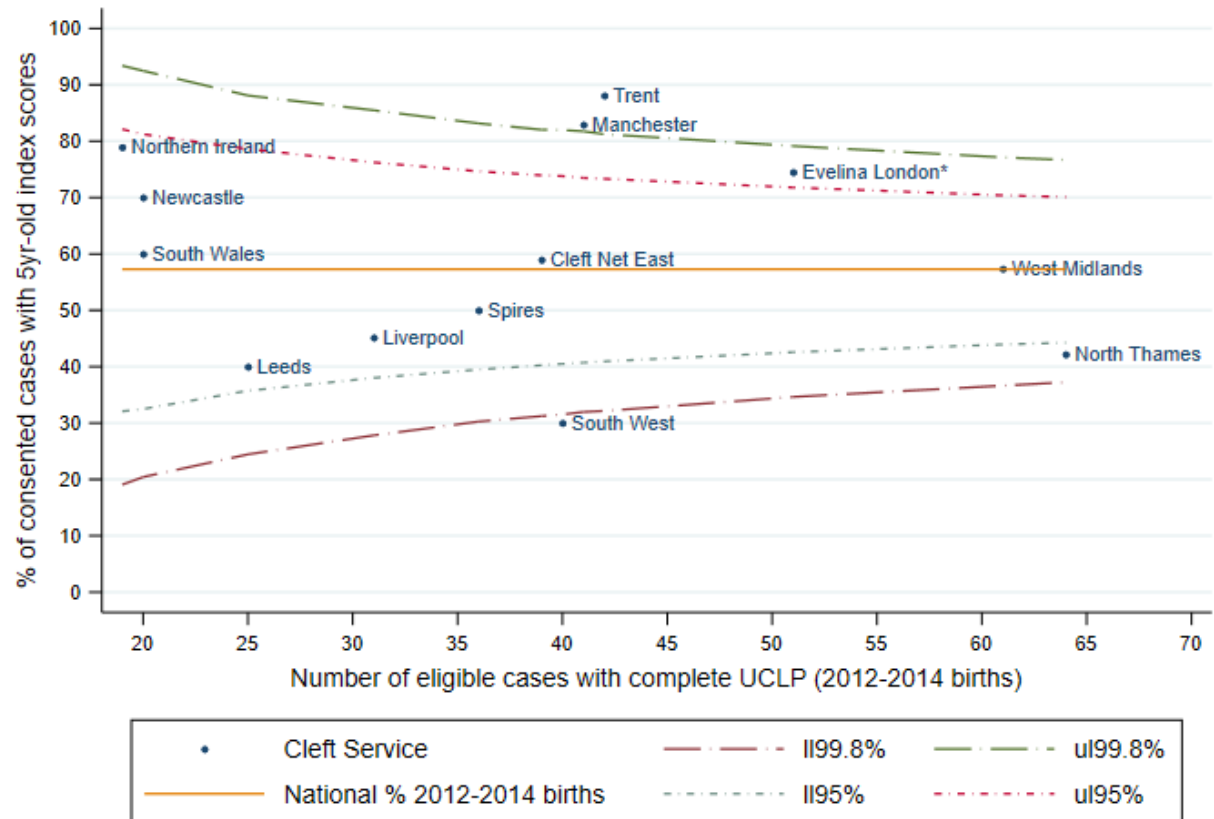


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- Trent and Manchester +ve outliers
- South West –ve outlier



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

Good facial growth - 2012-2014 births

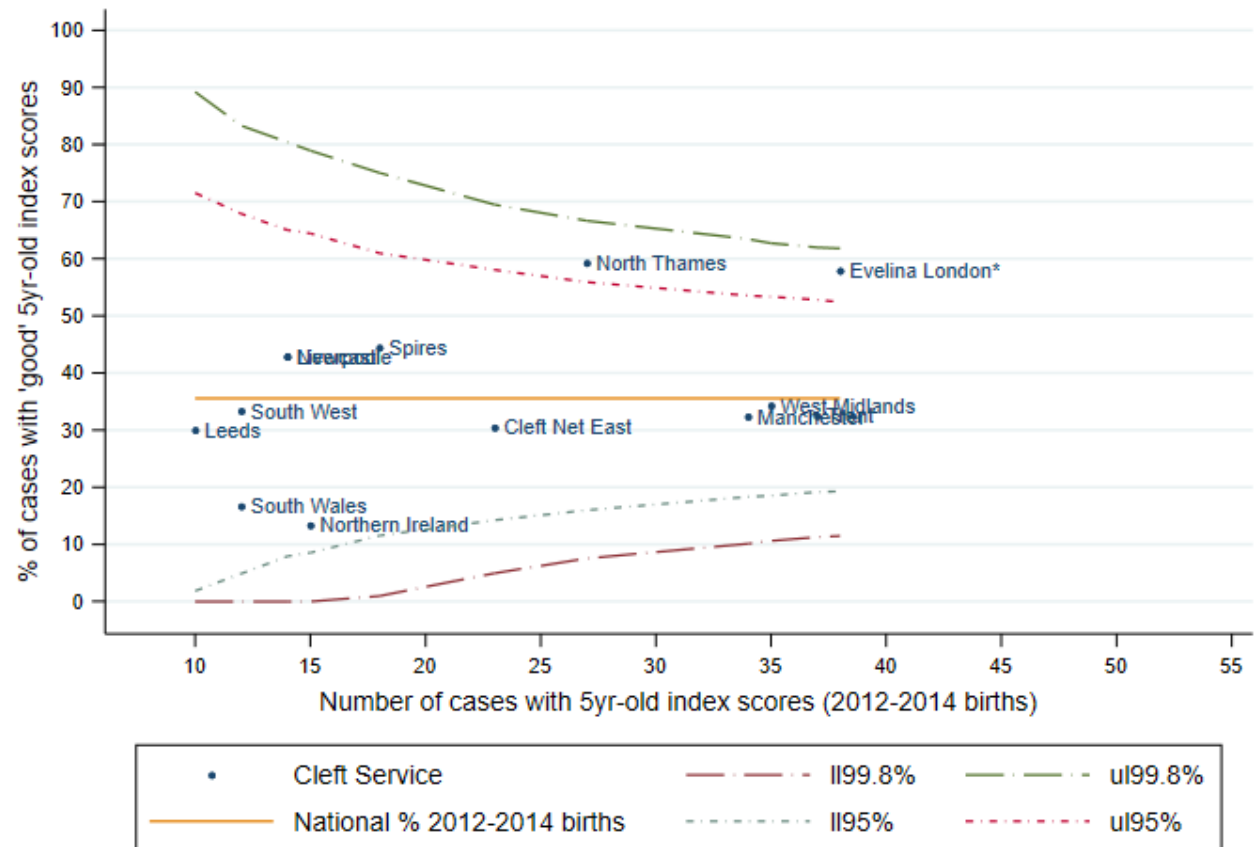


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- Average similar
- N. Thames and Evelina positive alerts
- No negative alerts



Note: Data from Evelina London and South West was not used to create funnel plot due to poor consent/data completion rate.

Speech data completeness - 2012-2014 births

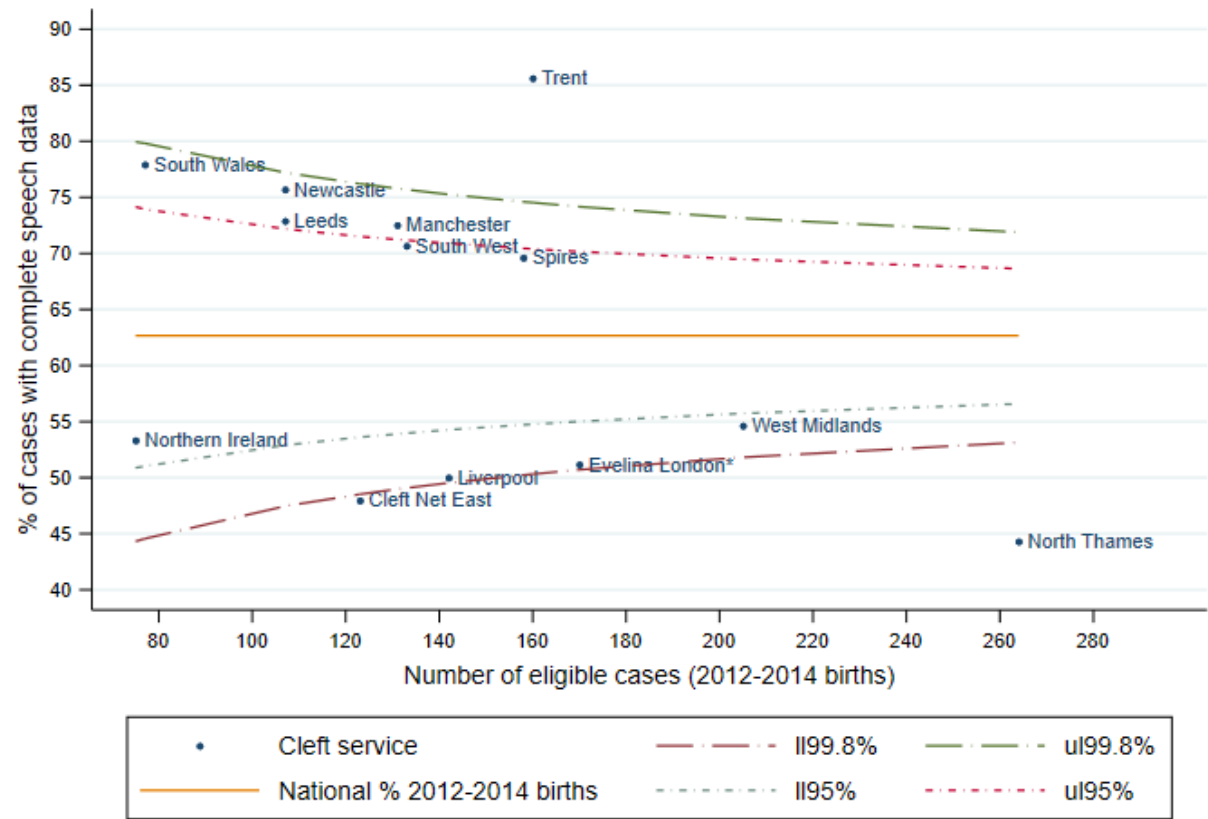


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- Newcastle and Leeds no longer +ve outliers
- N. Thames remains -ve outlier
- Cleft Net East now -ve outlier
- Liverpool and Evelina on the line



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

Speech data standard 1 - 2012-2014 births

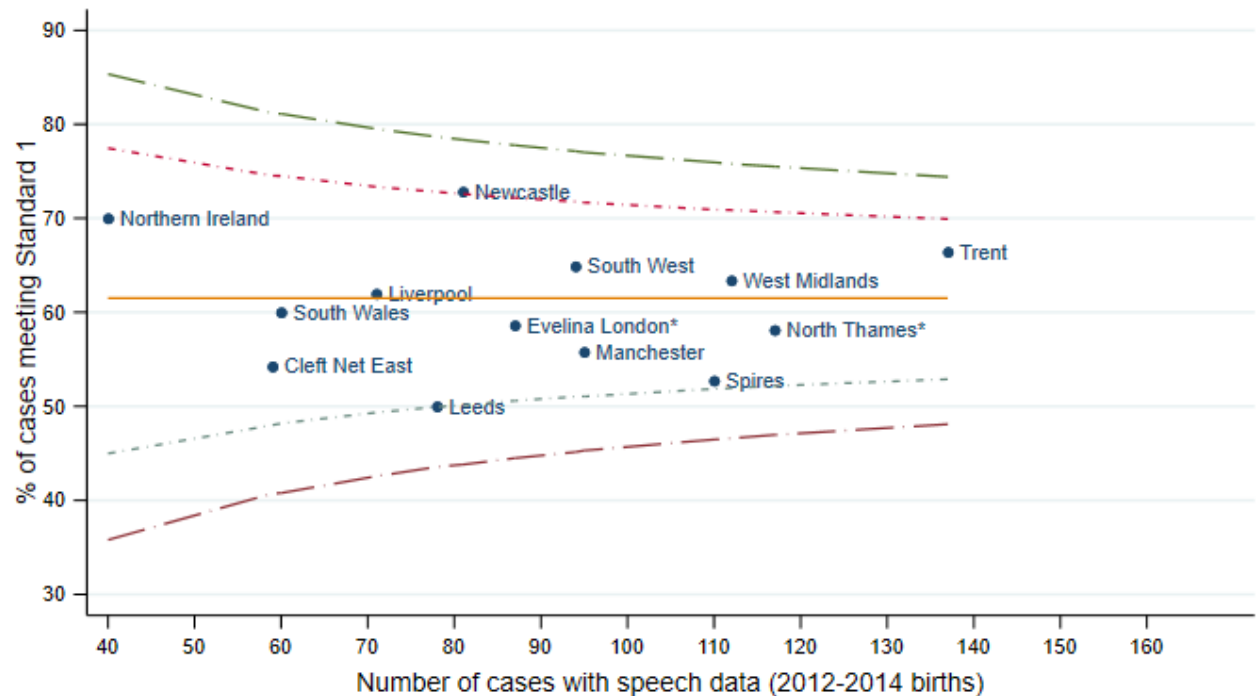


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- All within the funnel
- Average remains just above 60%



Note 1: Data from Evelina London Cleft Service were not used to create funnel plot due to poor consent verification rate.
 Note 2: Data from North Thames Cleft Service and Cleft Net East were not used to create funnel plot due to poor data completion rate.

Speech data standard 2a - 2012-2014 births

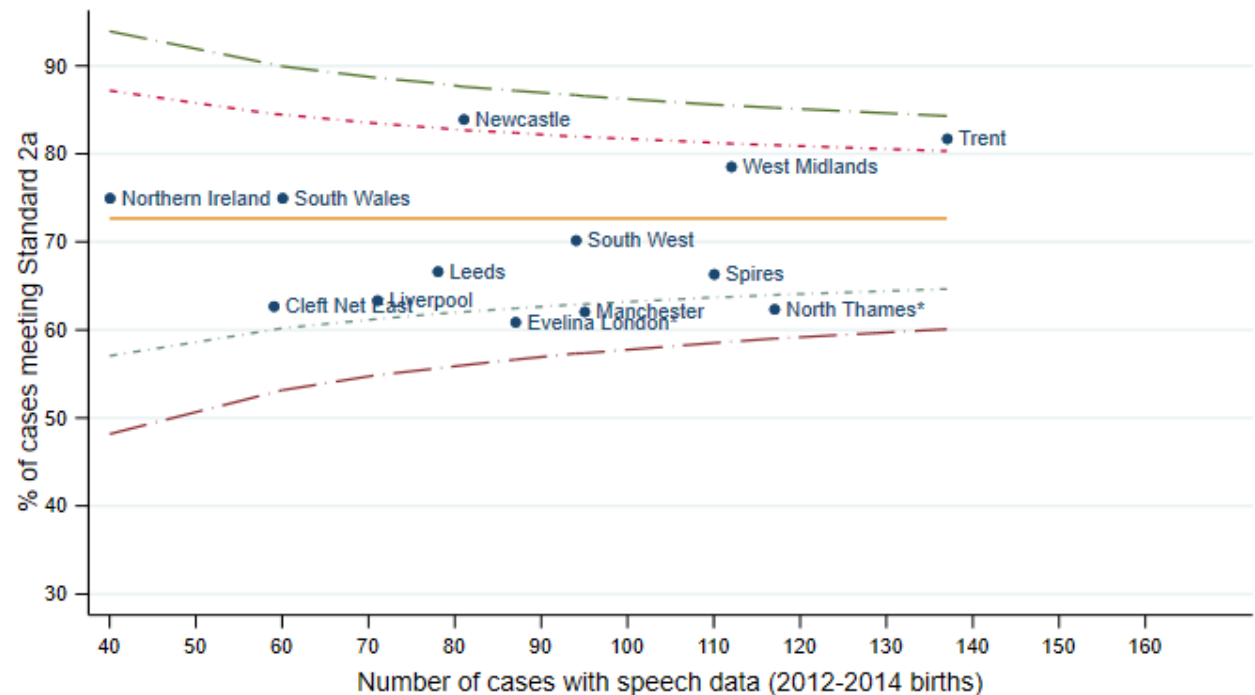


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- Average similar
- Trent no longer +ve outlier
- A few services remain in negative alert position



Note 1: Data from Evelina London Cleft Service were not used to create funnel plot due to poor consent verification rate.
 Note 2: Data from North Thames Cleft Service and Cleft Net East were not used to create funnel plot due to poor data completion rate.

Speech data standard 3 - 2012-2014 births

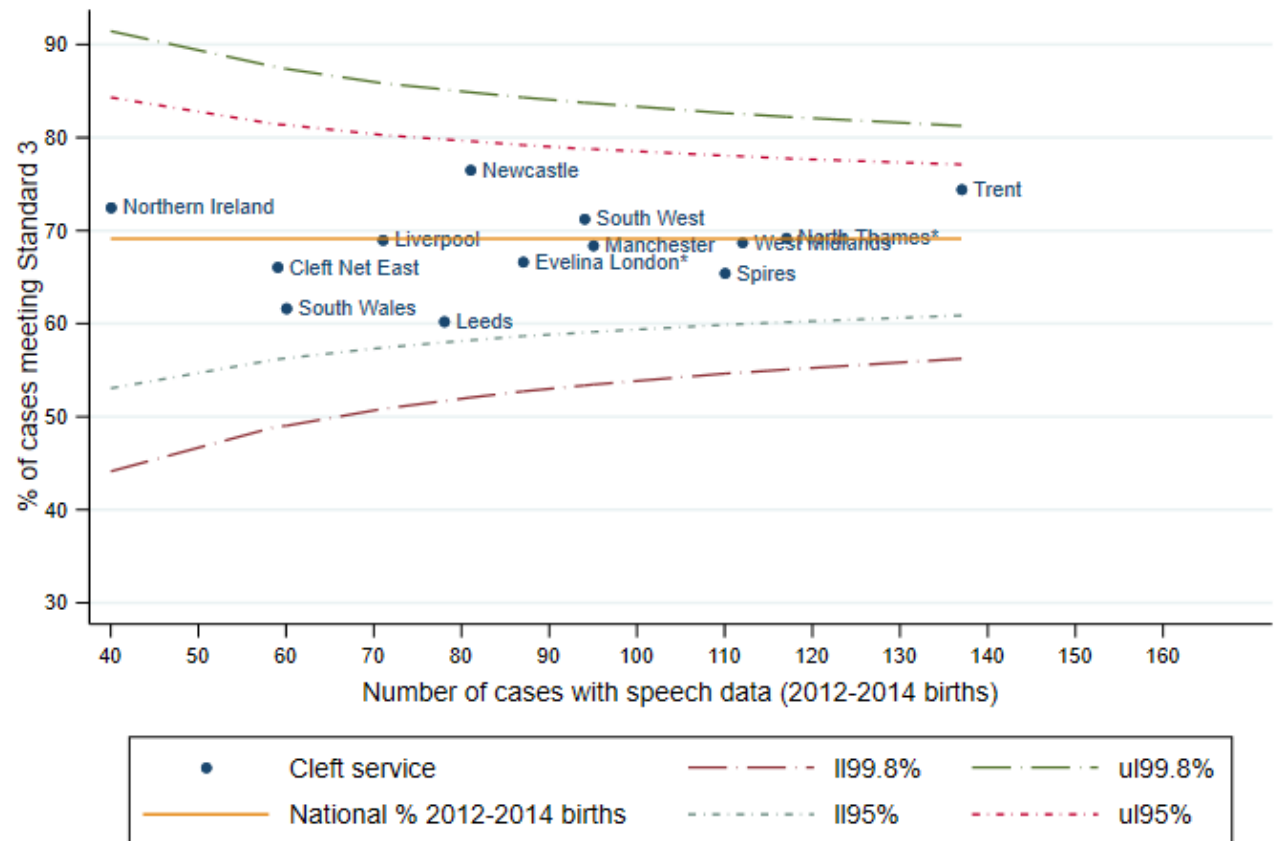


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- Average similar
- All within the funnel



Note 1: Data from Evelina London Cleft Service were not used to create funnel plot due to poor consent verification rate.
 Note 2: Data from North Thames Cleft Service and Cleft Net East were not used to create funnel plot due to poor data completion r

Psychology completeness - 2012-2014 births

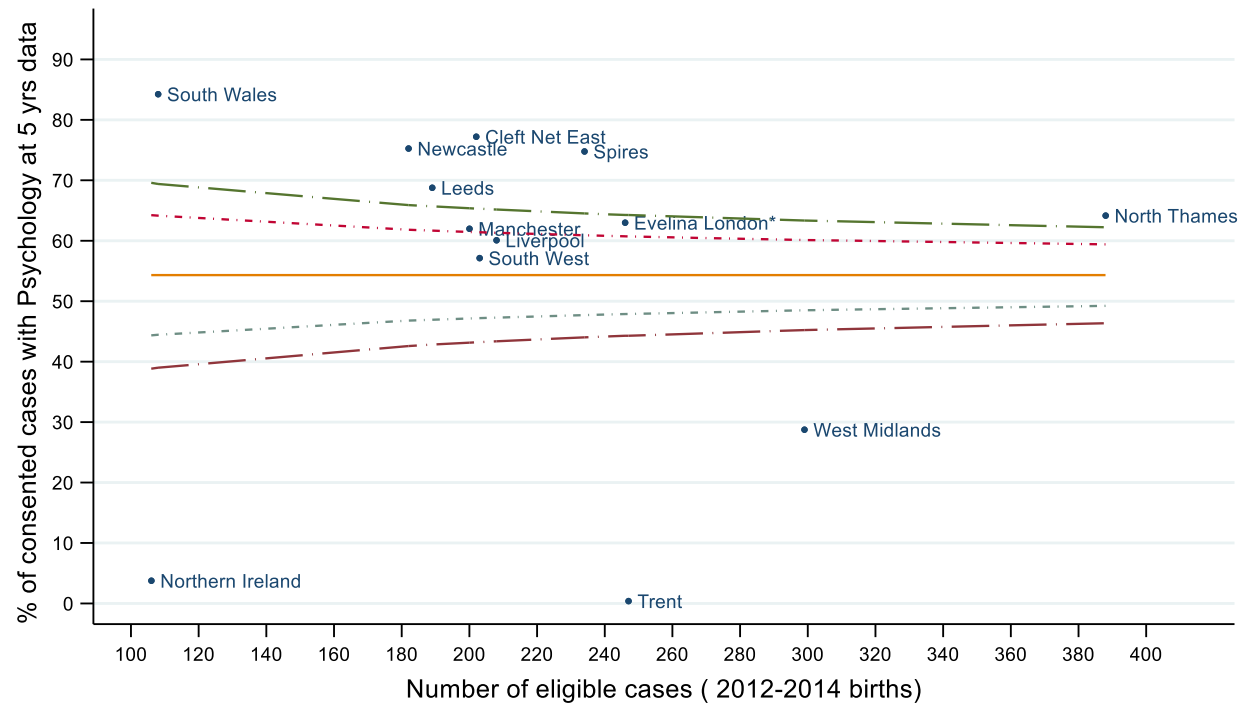


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- CleftNetEast and Spires now +ve outliers
- Evelina +ve alert
- W Mids –ve outlier
- Liverpool no longer +ve outlier
- S West no longer +ve alert



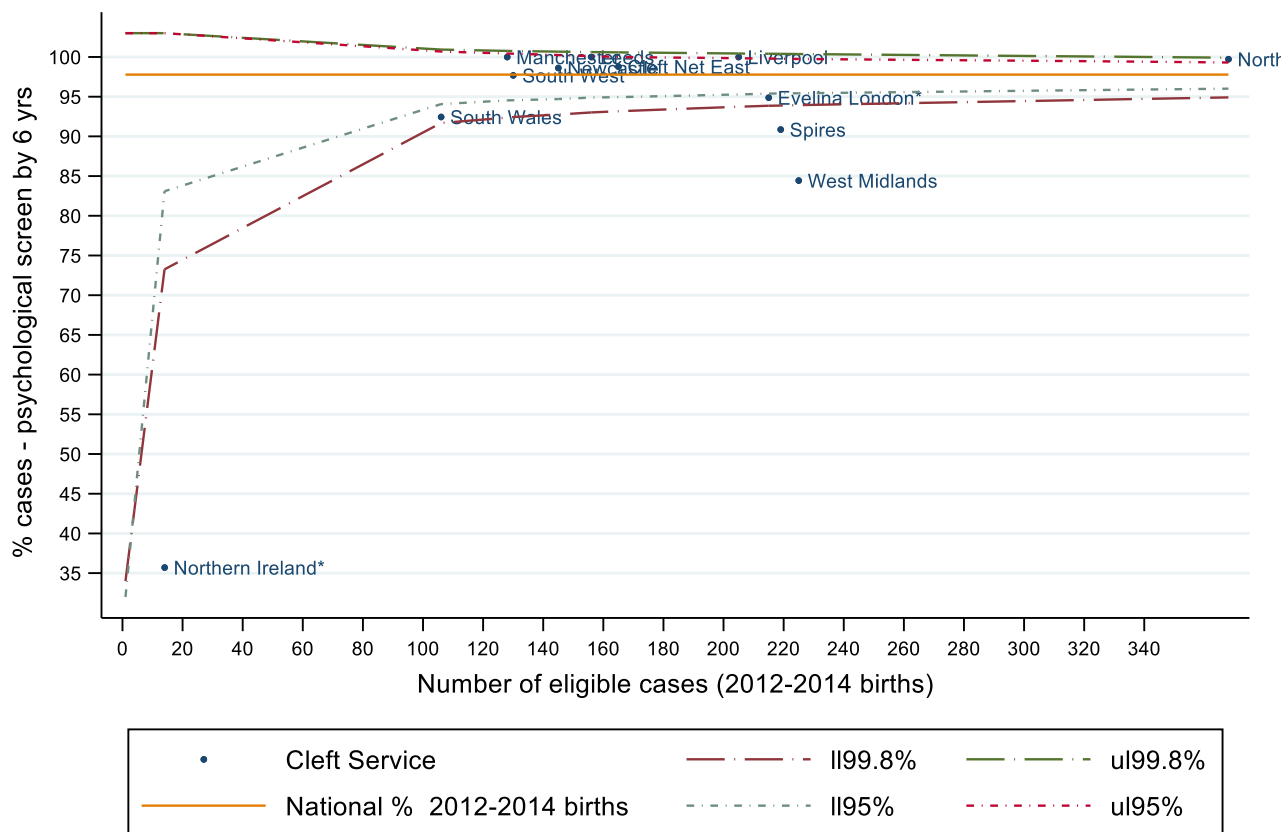
Note: Data from Evelina London was not used to create funnel plot due to poor consent verification rate.

Screen by 6y 2022

- national average up 1%



- +ve outliers remain the same
- NI now -ve outlier (82% to 35%)
- S Wales and Evelina -ve alerts
- Changed shape of funnel

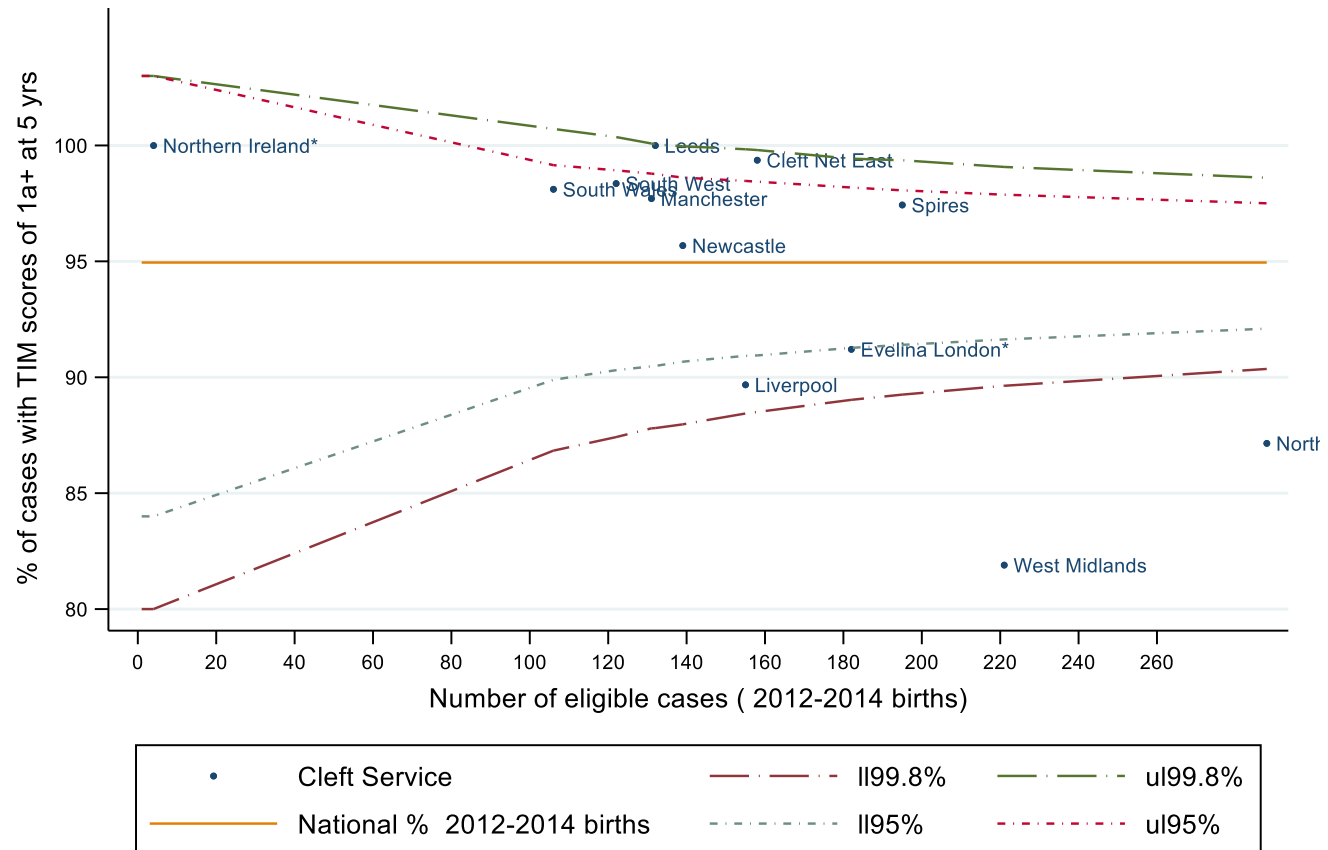


Note 1: Data from Evelina London was not used to create funnel plot due to poor consent verification rate.
 Note 2: Data from Trent, W Mids & N.I. were not used to create funnel plot due to poor data completion rates.

TIM 1a+ - 2012-2014 births



- National average up 2%
- Leeds is no longer +ve outlier but still +ve alert
- W Mids and N. Thames –ve outliers
- Liverpool –ve alert
- Trent n=1 not visible



Note 1: Data from Evelina London was not used to create funnel plot due to poor consent verification rate.
 Note 2: Data from Trent, W Mids & N.I. were not used to create funnel plot due to poor data completion rates.

SDQ High/VHigh - 2012-2014 births

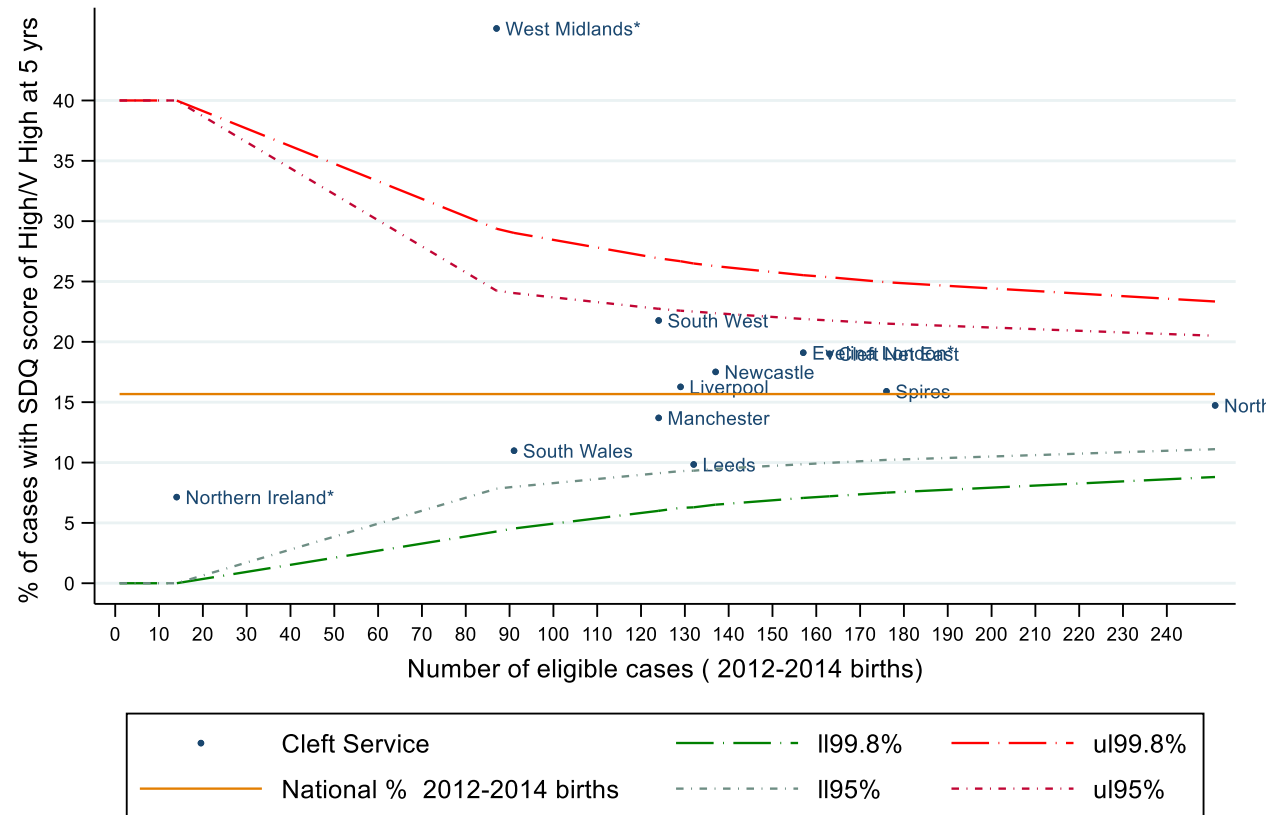


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- Evelina no longer -ve outlier
- W Mids -ve outlier
- Trent n=1 not visible



Note 1: Data from Evelina London was not used to create funnel plot due to poor consent verification rate.
 Note 2: Data from Trent, W Mids & N.I. were not used to create funnel plot due to poor data completion rates.



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Learning from good practice and challenges



Sharing learning and good practice



Speakers

1. Diane Phare – consent verification data completeness (Manchester)
2. Pamela Larmour – dental outcome data completeness (Belfast)
3. Melanie Stern – facial growth outcome data completeness (Trent)
4. Michaela Rowe – child growth and speech outcome data completeness (South Wales)
5. Fiona McKendrick – psychology outcome data completeness (Newcastle)
6. Priya Haria – response to the CRANE outlier process (North Thames)



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Question and Answer session





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Database Developments



Recent CRANE developments



The capture of

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

Syndromes



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Changed to capture via

- 10 Categories
- Including 'other' and clarification by free text

If syndrome/additional diagnosis is 'Yes, unknown name' please specify affected system(s):

Circulatory/cardiovascular system

Digestive/excretory system

Endocrine system

Nervous system

Renal system

Respiratory system

Skeletal system

Other (please specify below)

Description of affected systems



Syndromes - completeness



- Total cases with data n=5,171 / 23,566
 - 22% completeness for 1 Jan 2000 – 24 Jan 23 births*
- Data completeness, of the 5,171
 - 77% no reported syndromes
 - 23% syndromes (22% named, 1% unknown name)
- Therefore 5% of CRANE cohort is reported to have a syndrome
 - Mindful there can be a lag in formal diagnoses
- Where nothing entered, child assumed non-syndromic for analyses
- Thanks to Newcastle for 66% completeness for 2000-23*



Syndromes – for 2014-16



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- Total cases with data n=749 / 3,301
 - 23% completeness for 1 Jan 2014 – 31 Dec 2016
- Data completeness, of the 749
 - 65% no reported syndromes
 - 35% syndromes (31% named, 4% unknown name)
- Therefore 8% of 2014-16 births are reported to have a syndrome
- Thanks to Liverpool for 81% completeness for 2014-16



Ethnicity



- Total cases with data n=1,269
- Data completeness
 - 5% completeness for 1 Jan 2000 – 24 Jan 23 births*
 - 56% for 2022 births (48%, 2021)
 - Thanks to Trent (93%) and Leeds (100%) for 2022 records
- What this tells us so far
 - 83% white and 17% non-white ethnic background



Developmental Defects of Enamel (DDE)



- Guides, data collection forms and data dictionary
- Preliminary information in completeness – April 2023
- Soon to be updated – normal SN = score of 1

Paediatric dentistry: Developmental Defects of Enamel (DDE)

Please select one of the options below for each dental region: ⓘ

	SN (Right)	URB	URA	ULA	ULB	SN (Left)
Normal	●	●	●	●	●	●
Hypomineralisation	●	●	●	●	●	●
Hypoplasia	●	●	●	●	●	●
Abnormal shape/size	●	●	●	●	●	●
Congenitally missing	●	●	●	●	●	●
Unable - restored	●	●	●	●	●	●
Unable - carious	●	●	●	●	●	●
Unable - extracted	●	●	●	●	●	●
Unable - exfoliated	●	●	●	●	●	●
Not present	●	●	●	●	●	●
DDE Score subtotals						
Total 5 year DDE score						
Date record taken						



Database development: Next steps



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- Psychology at 10 and 15 years
- LAHSAL and LAHSHAL work
- Surgical procedures via HES
- New orthodontic outcomes
- New audiology outcomes
- Linkage - Newborn Hearing Screening Programme (NHSP)





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Quality Improvement Resources



Improving your data



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<https://www.crane-database.org.uk/resources/crane-data-dictionary/>

Data Dictionary

Data Collection Forms

CRANE Data Dictionary & Data Collection Forms

Click on the image below to download your copy of the CRANE Data Dictionary

Code	Description
1, ethnicity	An individual's race/ethnicity.
2, ethnicity	Referring to the patient's race/ethnicity. (This is the same as the patient's ethnicity.)
3, ethnicity	An individual's race/ethnicity. This field requires a patient to be registered with the patient's CRANE source Health data.
4, ethnicity	An individual's race/ethnicity. This field requires a patient to be registered with the patient's CRANE source Education data.
5, ethnicity	An individual's race/ethnicity. This field requires a patient to be registered with the patient's CRANE source Education data.

This document (above) provides information on all data items collected by the CRANE Database.

Last updated July 2022:

- The Database started collecting data on Developmental Defects of Enamel (DDE) at 5 and 10 years of age, dental health outcome information, in May 2022. Corrections to the information for this section were made in July 2022.

Previous key updates – 2021:

- Collection of 'Syndromes' via drop down menus, to allow the recording of a syndrome or congenital abnormality for consented cases.
- Collection of information on ethnic group from the 1 April 2021. In line with the **mandatory recording of ethnicity within National Clinical Databases**. In response to one of the eight key actions set out in July 2020 as part of the NHS response to COVID-19. To help clinicians, provider organisations and commissioners understand and address health inequality.

The data collected by the CRANE Database is also detailed in **CRANE Data Collection Forms** on:

- Patient registration (Form 1), and outcomes (Form 2). These are available to download below.

[Download Form 1 – Patient registration](#)

[Download Form 2 – Outcomes](#)

Improving your data



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<https://www.crane-database.org.uk/resources/>

11 x Guides

Resources

Filter resources

- Professional
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Filter by type

- Infographics
- Data
- Guidance
- Guidance - Videos
- Quality Improvement
- Templates & Proformas
- Governance
- Policies

Submit

Posted 23 September 2022 in [Guidance](#).

[Guide: Registering for an account](#)

Posted 23 September 2022 in [Guidance](#).

[Guide: Complying with the National Data Opt-out](#)

Posted 30 August 2022 in [Data](#), [Guidance](#), and [Templates & Proformas](#).

[Guide: Psychology outcomes data entry](#)

Improving your data



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<https://www.crane-database.org.uk/resources/>

6 x Video demonstrations

Resources

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- Guidance - Videos
- Quality Improvement
- Templates & Proformas
- Governance
- Policies

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[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](#)

Improving your data



- Try to complete workbooks shared with services March 2022
- These contained missing or potentially incorrect data flagged within our system
- Correcting these errors will improve the accuracy of the data used for future research



Local action plan



<https://www.crane-database.org.uk/resources/crane-local-action-plan-2022/>

To drive quality improvement

Cleft Team Local Action Plan for responding to CRANE 2022 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 – Specific, Measurable, Assignable, Realistic, Time-related.	
Note: Data relating to each recommendation listed below can be found in the 'CRANE 2022 Annual Report' here: https://www.crane-database.org.uk/reports/crane-database-2022-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.	

Patient transfers



- Some concerns from CEN groups about patients from other services being included in outcome reporting
- For managing transfers use the relevant guides and video demonstrations
 - Video <https://www.crane-database.org.uk/resources/video-demonstration-managing-patient-transfers/>
 - Guide <https://www.crane-database.org.uk/resources/guide-quick-reference-for-managing-patient-records/>



Transfers



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CRANE Transfers To Recipient Centre by Year of Birth

As at 4th Oct 2022

Transferred to	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022	Total	
Belfast	0	0	0	0	0	0	0	1	0	0	1	0	0	0	1	0	0	0	0	0	0	1	0	4	
Birmingham	0	0	0	0	1	0	1	0	3	1	2	0	0	3	3	1	4	3	1	0	0	0	0	0	23
Bristol	2	2	3	2	0	2	1	1	2	4	2	5	8	4	4	4	2	2	1	1	2	1	0	1	55
Cambridge	0	0	1	0	0	3	0	0	5	1	1	3	1	5	5	2	3	1	1	5	1	1	1	1	40
Chelmsford	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	1	1	1	1	1	0	0	0	1	7
Great Ormond St	0	0	0	0	1	0	0	0	1	2	3	0	0	2	2	6	0	2	3	0	1	7	2	32	
Guy's and St. Thomas' Trust	0	0	0	0	0	0	1	0	2	0	2	1	1	2	3	1	3	1	2	3	0	0	0	0	22
Leeds	0	0	0	0	0	0	0	2	1	2	3	2	1	4	2	4	5	1	0	3	1	1	0	0	32
Liverpool	0	0	0	1	0	1	0	0	1	1	0	2	7	5	1	3	6	5	2	1	0	3	0	0	39
Manchester	0	0	0	0	0	0	0	1	0	0	0	3	3	3	2	2	7	3	2	2	1	1	1	1	31
Newcastle	0	2	0	0	1	2	0	2	4	2	1	4	1	5	1	3	3	3	2	2	3	1	0	0	42
Nottingham	0	1	0	2	1	1	2	5	3	1	2	5	1	2	1	5	5	5	6	6	1	0	0	0	55
Oxford	0	0	0	0	0	0	0	0	1	0	0	2	0	1	4	7	1	2	0	0	1	2	4	25	
Salisbury	0	2	0	0	0	0	1	0	0	0	1	3	1	3	3	0	4	3	1	0	0	0	0	0	22
Scotland	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	1	0	1	0	0	0	0	0	4
Swansea	0	0	0	0	0	0	0	0	0	2	3	1	2	2	2	1	1	0	1	4	0	1	0	0	20
	2	7	4	5	4	9	6	12	23	16	21	31	27	41	36	40	46	32	24	28	11	19	9	453	

- N = 55 is the largest number of transfers over 23 year period by service
- Average is 1-2 per service per year
- No significant impact on outcome reporting found

Births in UK



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15. Should families not based in England, Wales and Northern Ireland be included/excluded from being registered on the CRANE Database?

Patients who are not resident in England, Wales and Northern Ireland, should not be registered in the CRANE Database.

Specifically, the following children **should not** be registered in the CRANE Database, nor have outcome data collected in CRANE:

- Babies from parents not based in the UK, born with a cleft in a UK hospital who then returned to their home country. This is because CRANE is a registry for babies from families residing in England, Wales and Northern Ireland.
- Babies born outside of the UK with a cleft and who travel to the UK to receive cleft care services, from either the NHS or private cleft care providers, then return to their home country after their cleft care. Recording of this information would distort the estimation of incidence of cleft and evaluation of cleft care services in England, Wales and Northern Ireland.

Note: Where we have made reference to the United Kingdom (UK), in the text above for simplicity, we are referring to England, Wales and Northern Ireland. As these are the countries currently submitting data to the CRANE Database.

The current guidance by the Cleft Development Group is that patients from abroad are not registered in CRANE. Their treatment pathway started elsewhere and have not been accessing our health care system from birth. This is particularly important in the context of evaluating the burden on cleft team services.

<https://www.crane-database.org.uk/about/faq/professionals/>



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Important Dates



Timeline for 2023



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Cleft Registry and Audit Network (CRANE) ANALYSIS TIMELINE 2023: Including dates for outlier process

The graphic below outlines the timeline that CRANE will work in 2023.

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 31 December 2022 will be included in the 2023 preliminary report – used for preliminary identification of outliers – and included in the CRANE 2023 Annual Report.

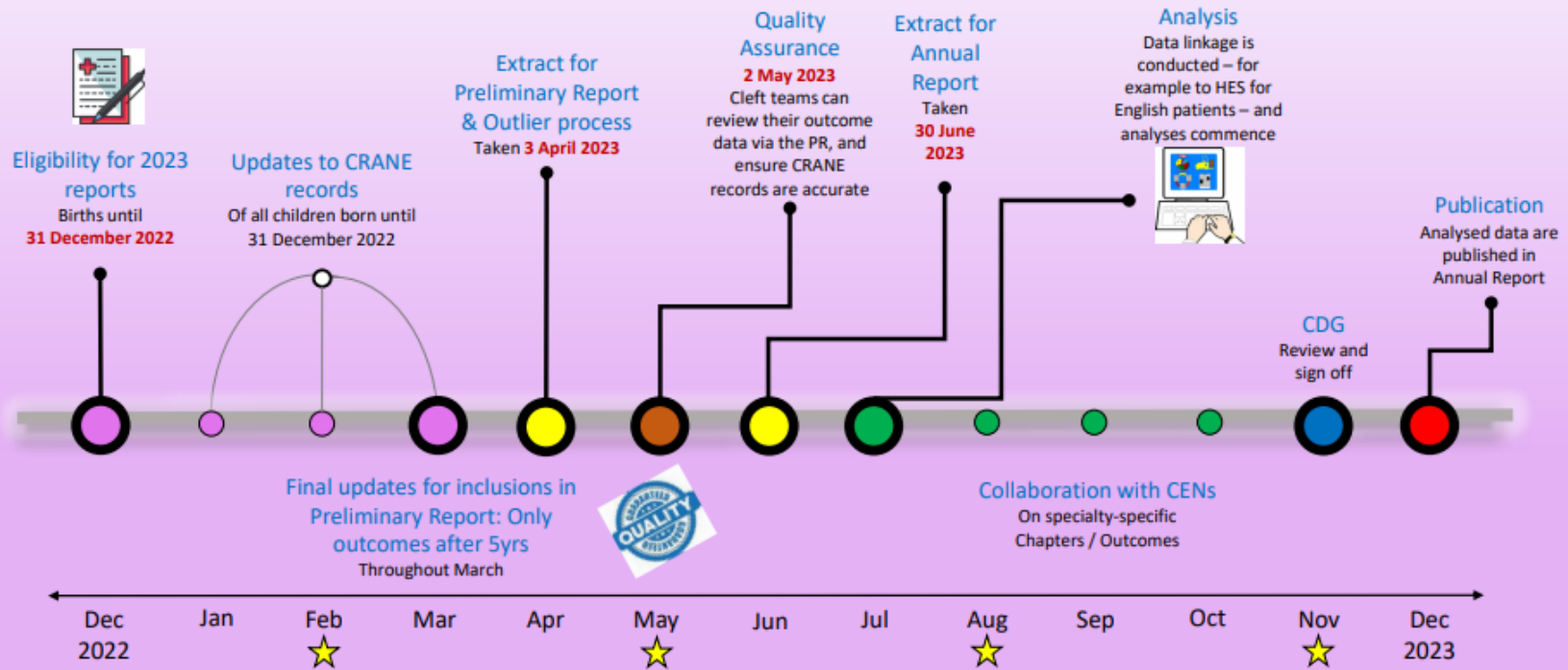
Once the data for the CRANE 2023 Annual Report has been analysed, the reports will be written. The final draft then will be agreed by key stakeholders, including the CDG, before publication in December 2023.

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 ●



<https://www.crane-database.org.uk/resources/data-collection-milestones-for-2023/>

Data submission deadlines



- Friday 24 February 2023 - Q3 2022/23 Dashboard
- Monday 3 April 2023 – Extract for Preliminary report
 - 5-year outcomes for 2014 to 2016 births
 - Registrations for 2020 to 2022 births
- Use our resources to check your data
- Contact crane@rcseng.ac.uk with queries

CFSGBI April 2023



CRANE



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- See you at CFSGBI in Cardiff in April 2023
- Several abstracts submitted - CRANE data



THE CRANIOFACIAL SOCIETY
OF GREAT BRITAIN AND IRELAND



Next meeting



28 February 2023 from 10:30

‘CRANE data Q & A’

For anyone who submits data



CRANE



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Thank you



crane@rcseng.ac.uk



[@CRANE News](https://twitter.com/CRANE_News)



<https://www.crane-database.org.uk/>

