CRANE 2024 Making it better session

22 Jan 2024

Craig Russell & Kate Fitzsimons

On behalf of the CRANE Database team

RCS
ADVANCING SURGICAL STANDARDS

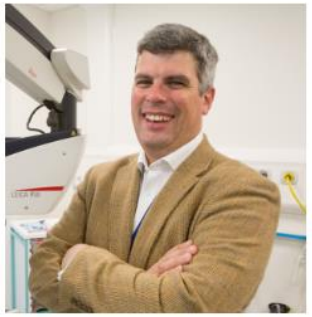
Welcome and Introductions

No recordings please

Alert

- Please remember when contacting CRANE about a patient
  - **Only use CRANE ID**
  - Never send patient identifiable information to our contact us page or via email:
    - NAME
    - DOB
    - HOSPITAL NUMBER

CRANE team



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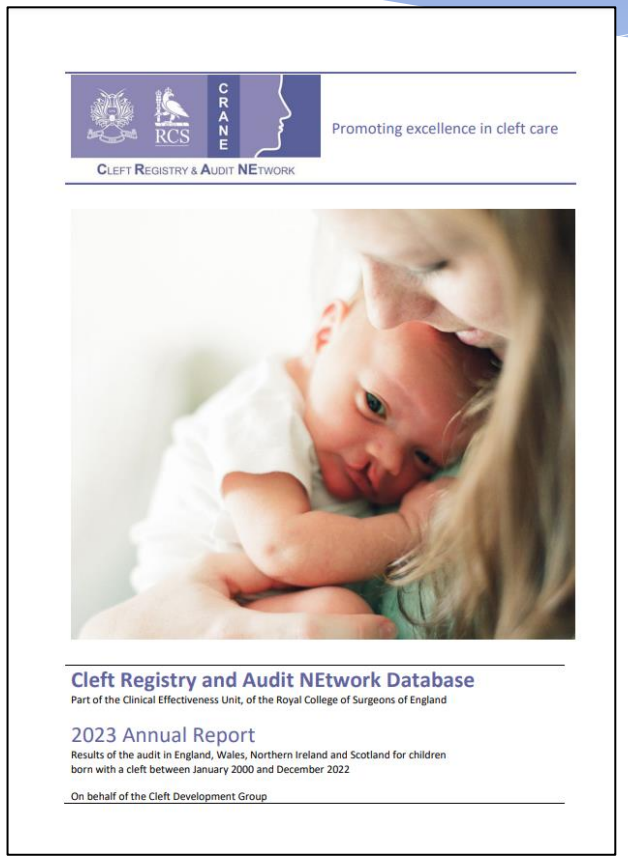
Aims

Provide stakeholders with an opportunity to share good practice and challenges relating to the submission of CRANE data

- Changes to the CRANE Annual Report
- Sharing local experiences:
  - Rapidly turning around low consent verification rate
  - Variability in Robin Sequence rates
  - Good practice recommendations for data completeness by services with positive outlier status
  - Barriers to data submission faced by services with negative outlier status
- Q&A
- CRANE updates and key dates.

CRANE Annual Report 2023

- Published December 2023
  - Registry information
  - Consent verification
  - 5-year outcomes
  - Development work
- Changes implemented to streamline report & make it as useful as possible



Promoting excellence in cleft care

Cleft Registry & Audit NEtwork

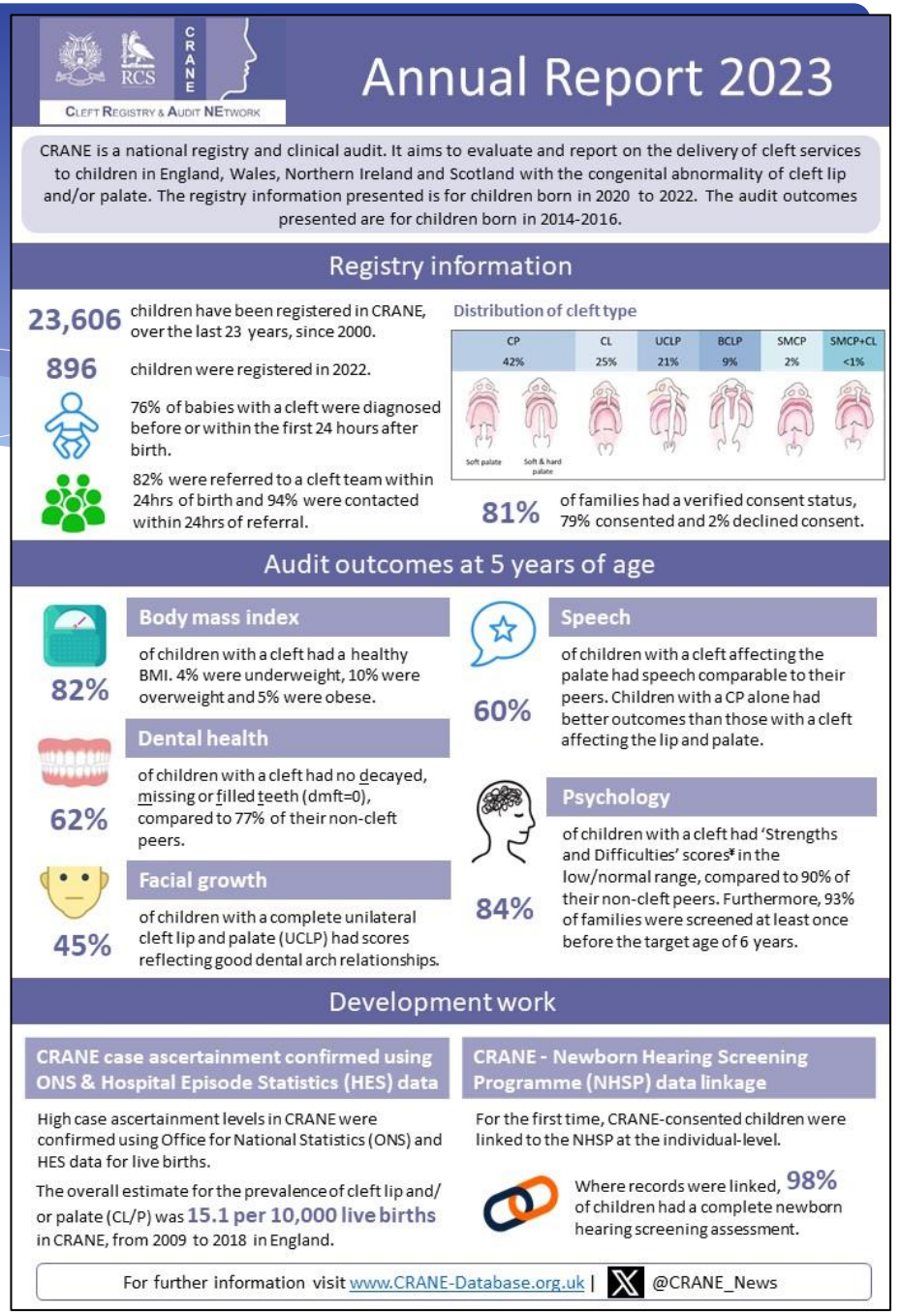
Cleft Registry and Audit NEtwork Database

Part of the Clinical Effectiveness Unit, of the Royal College of Surgeons of England

2023 Annual Report

Results of the audit in England, Wales, Northern Ireland and Scotland for children born with a cleft between January 2000 and December 2022

On behalf of the Cleft Development Group



Cleft Registry & Audit NEtwork

Annual Report 2023

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, Northern Ireland and Scotland with the congenital abnormality of cleft lip and/or palate. The registry information presented is for children born in 2020 to 2022. The audit outcomes presented are for children born in 2014-2016.

Registry information

23,606 children have been registered in CRANE, over the last 23 years, since 2000.

896 children were registered in 2022.

76% of babies with a cleft were diagnosed before or within the first 24 hours after birth.

82% were referred to a cleft team within 24hrs of birth and 94% were contacted within 24hrs of referral.

Distribution of cleft type

CP	CL	UCLP	BCLP	SMCP	SMCP+CL
42%	25%	21%	9%	2%	<1%

Soft palate | Soft & hard palate

81% of families had a verified consent status, 79% consented and 2% declined consent.

Audit outcomes at 5 years of age

Body mass index

82% of children with a cleft had a healthy BMI. 4% were underweight, 10% were overweight and 5% were obese.

Dental health

62% of children with a cleft had no decayed, missing or filled teeth (dmft=0), compared to 77% of their non-cleft peers.

Facial growth

45% of children with a complete unilateral cleft lip and palate (UCLP) had scores reflecting good dental arch relationships.

Speech

60% of children with a cleft affecting the palate had speech comparable to their peers. Children with a CP alone had better outcomes than those with a cleft affecting the lip and palate.

Psychology

84% of children with a cleft had 'Strengths and Difficulties' scores* in the low/normal range, compared to 90% of their non-cleft peers. Furthermore, 93% of families were screened at least once before the target age of 6 years.

Development work

CRANE case ascertainment confirmed using ONS & Hospital Episode Statistics (HES) data

High case ascertainment levels in CRANE were confirmed using Office for National Statistics (ONS) and HES data for live births.

The overall estimate for the prevalence of cleft lip and/or palate (CL/P) was **15.1 per 10,000 live births** in CRANE, from 2009 to 2018 in England.

CRANE - Newborn Hearing Screening Programme (NHSP) data linkage

For the first time, CRANE-consented children were linked to the NHSP at the individual-level.

Where records were linked, **98%** of children had a complete newborn hearing screening assessment.

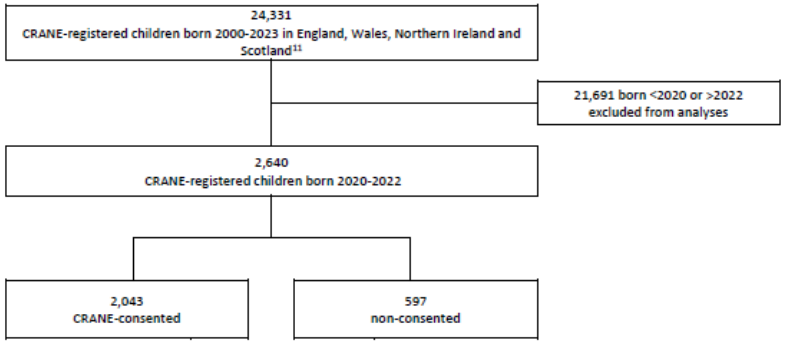
For further information visit www.CRANE-Database.org.uk | @CRANE_News

New flow charts showing included cases

3. Registry information

This chapter details the characteristics of CRANE-registered children born with a cleft lip and/or palate in 2020-2022. The timing of diagnosis, referral to Cleft Services and contact with families is also provided. This is key information for cleft care planning. Figure 3.1 details the children eligible for reporting.

Figure 3.1. CRANE cohort eligible for inclusion in this chapter.



Characteristic	CRANE-consented N=2,043 (77%)	CRANE non-consented N=597 (23%)
Cleft type	✓	✓
Robin Sequence	Cleft palate alone	Cleft palate alone
Sex	✓	✓
Gestation*	✓	
Birthweight*	✓	
Diagnosis timing	✓	✓
Referral	✓	✓
Contact	✓	✓

Legal basis for data collection and analysis: The data used for this section are collected for all registered cases under a 'Section 251' exemption (of the NHS Act 2006 and its current regulations, the Health Service (Control of Patient Information (CPI)) Regulations 2002), with approval from the Confidentiality Advisory Group (CAG) for the disclosure of CPI held by the CRANE Database.

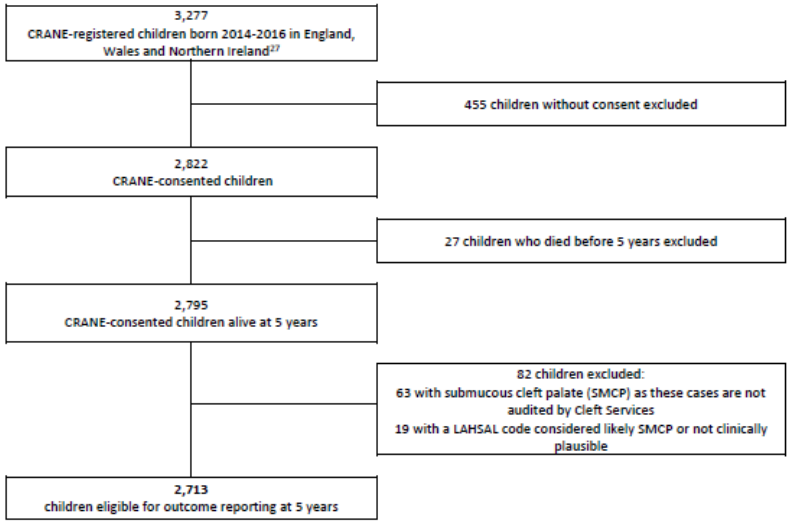
*Gestation and birthweight is an exception to the Section 251 exemption and is collected for all children whose families have given informed consent to outcomes data collection by the CRANE Database.

[11] Scotland joined in January 2023 so have one year (births in 2022) of registrations only.

5. Audit outcomes at 5 years of age

This chapter presents cleft-related 5- year outcomes for CRANE-consented children, born 2014 to 2016. Figure 5.1 details the eligible cohort and the outcomes collected.

Figure 5.1. CRANE cohort eligible for 5-year outcome reporting.



Outcome	CLO N=683 (25%)	CPO N=1,149 (42%)	UCLP N=587 (22%)	BCLP N=261 (10%)	Non-specified N=33 (1%)
Child growth	✓	✓	✓	✓	✓
Dental health	✓	✓	✓	✓	✓
Facial growth			Complete UCLP only		
Speech		✓	✓	✓	
Psychology	✓	✓	✓	✓	✓

Legal basis for data collection and analysis: The data used for this section are collected for all children whose families have given informed consent to outcomes data collection by the CRANE Database.

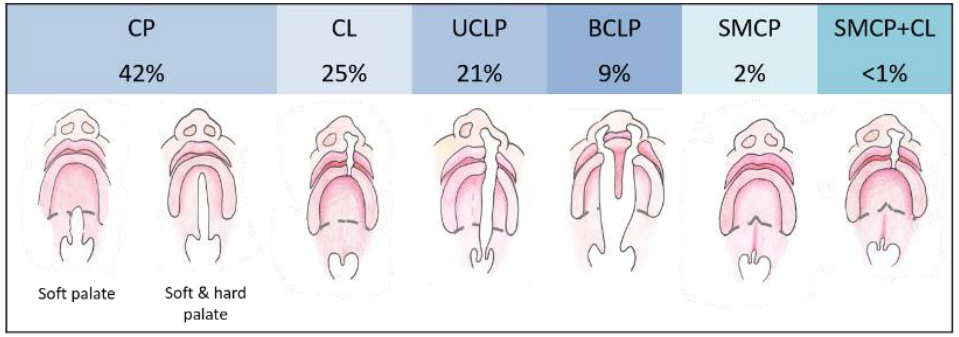
[27] Scotland joined CRANE in January 2023 and therefore have no eligible cases for outcome reporting.

Cleft type distribution

3.1.1 Cleft type

Data completeness: Cleft type specification	
Notes	Cleft type is based on the LAHSAL code provided. Where this is not available, services can select cleft type from a drop-down menu. LAHSAL code is important because it provides information on the laterality of the cleft lip and the completeness of the cleft.
Denominator	2,640 CRANE-registered children
What did we find?	• 93% of CRANE-registered children had their cleft type specified (Cleft Service range: 69%-100%, p<0.001). This compares to 92% of those born 2018-2020. • Reporting did not vary significantly according to birth year (p=0.202).

Outcome: Cleft type distribution and cleft characteristics	
Denominator	2,459 children with cleft type reported
What did we find?	• 42% of children had a cleft palate alone (CP). • 25% of children had a cleft lip alone (CL). Of these, 58% were left-sided, 33% were right-sided and 8% were bilateral. Among those with a unilateral CL, the left:right ratio was 63%:37%. • 21% of children had a unilateral cleft lip and palate (UCLP). The left:right ratio was 63%:37%. Overall, 71% had a complete UCLP[13]. • 9% of children had a bilateral cleft lip and palate (BCLP). 46% had a complete BCLP. • 2% of children had a submucous cleft palate (SMCP) alone. • <1% of children had a submucous cleft palate with cleft lip (SMCP+L) • There were no significant differences in the distribution of the four main cleft types (CL, CP, UCLP & BCLP) across Cleft Services (p=0.576); however, Northern Ireland registered a much higher proportion of children with SMCP (22% of their registrations) than the overall average (2% of registrations).



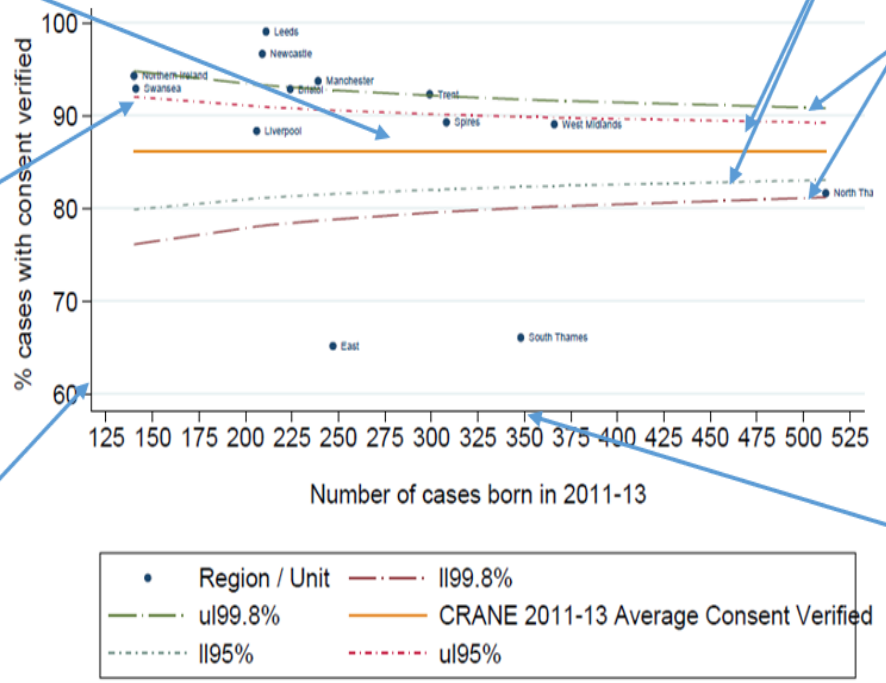
New funnel plots in registration chapter

- Funnels were previously restricted to data items subject to the outlier policy
- New funnel plots introduced for data items that:
  - show variability between services
    - Robin sequence
    - Data completeness for gestational age & birthweight
  - are key indicators in early cleft care:
    - Diagnosis time
    - Referral
    - Contact

Interpreting 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



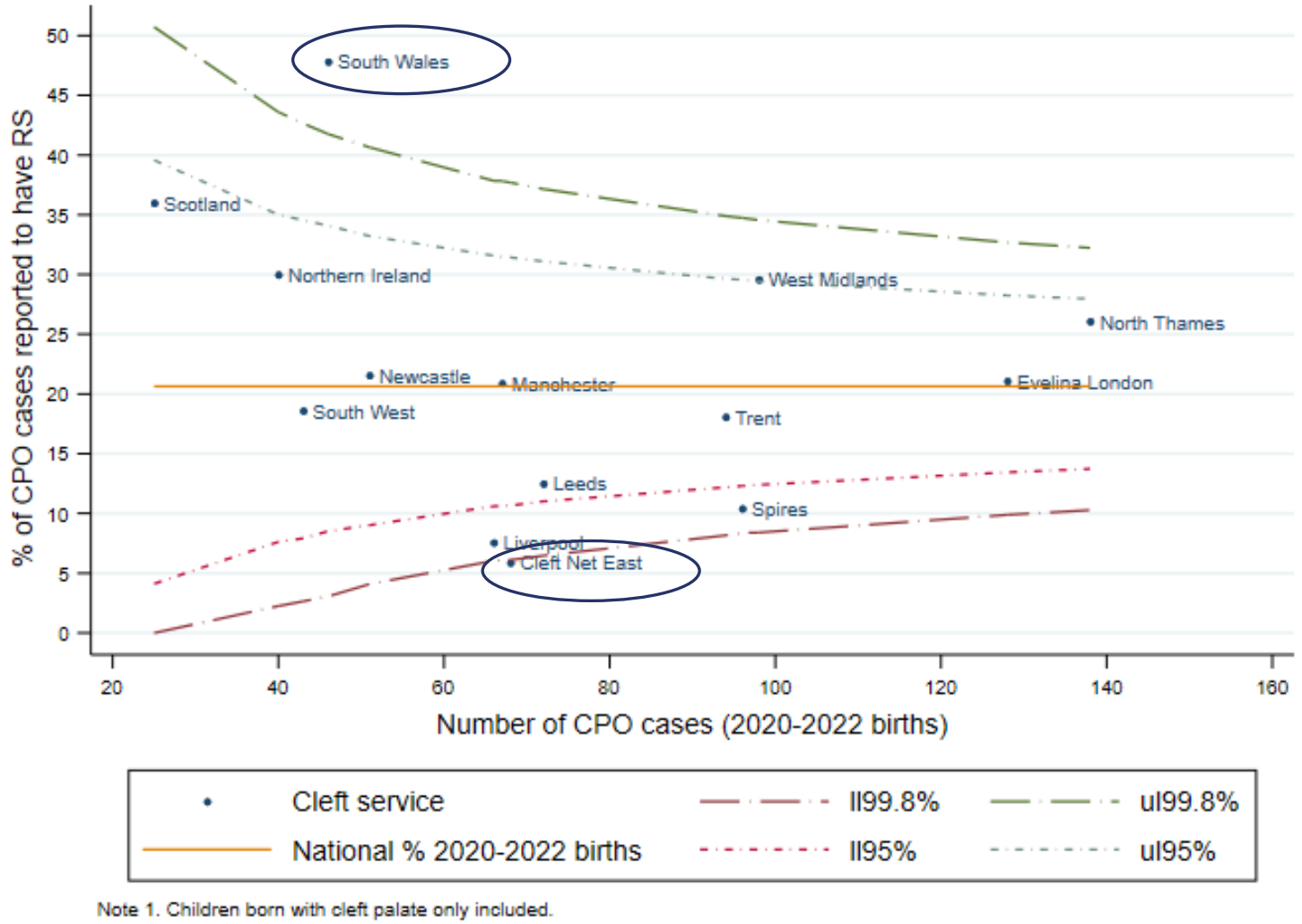
- Inner lines show two standard deviations or 95% control limits
- Outer lines represent three standard deviations or 99.8% control limits
- The funnel shape is formed because the control limits get narrower as the total number of patients in an organisation increases
- The size of the teams' cohort is shown on the horizontal or X axis

Robin Sequence

Data completeness: Robin Sequence status	
Notes	• For children with a cleft palate alone, services are required to report Robin Sequence (RS) status (present or absent). • RS is a congenital birth defect where micrognathia and glossoptosis appear together with cleft palate.
Denominator	1,032 CRANE-registered children with cleft palate alone (excludes those with SMCP)
What did we find?	88% of CRANE-registered children with cleft palate alone had their Robin Sequence status (present or absent) specified (Cleft Service range: 12%-100%, p<0.001).

Outcome: Prevalence of Robin Sequence among children with a cleft palate alone	
Notes	Not subject to outlier policy but funnel plot provided to demonstrate variation in rates across services.
Denominator	1,032 children with cleft palate
What did we find?	• 21% of children with cleft palate alone were reported to have RS (Cleft Service range: 6%-48%, p<0.001). The rate was 23% among those with a specified RS status (Cleft Service range: 10%-50%). • These rates equate to an average of 71 children born each year with RS. • 68% of children with cleft palate alone were confirmed as not having RS (Cleft Service range: 52%-90%[3]). A further 12% did not have their status confirmed and are therefore assumed not to have it.
Outliers	Positive: 1. South Wales (48%) Negative: 1. Cleft Net East (6%)

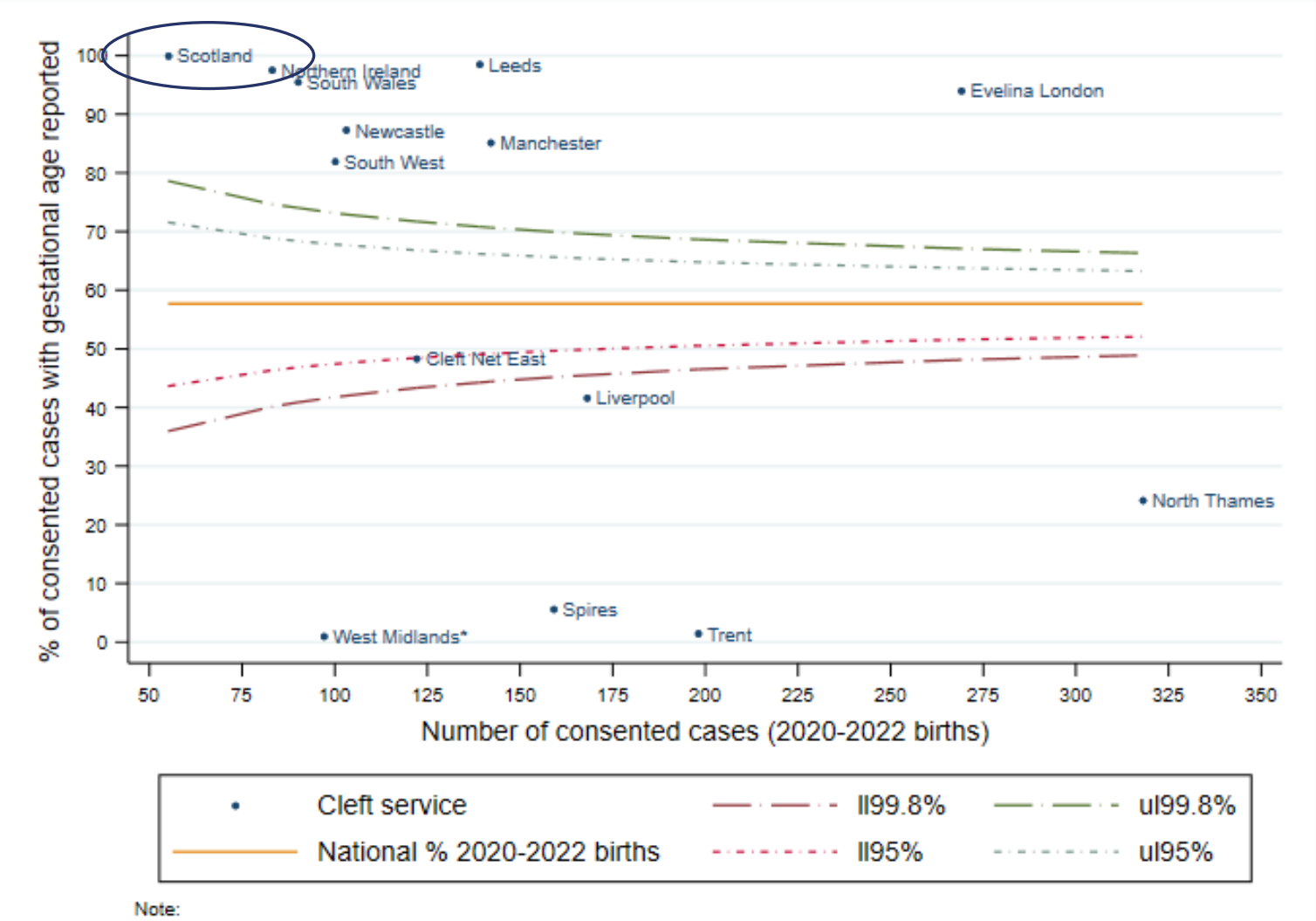
Robin Sequence



Note 1. Children born with cleft palate only included.

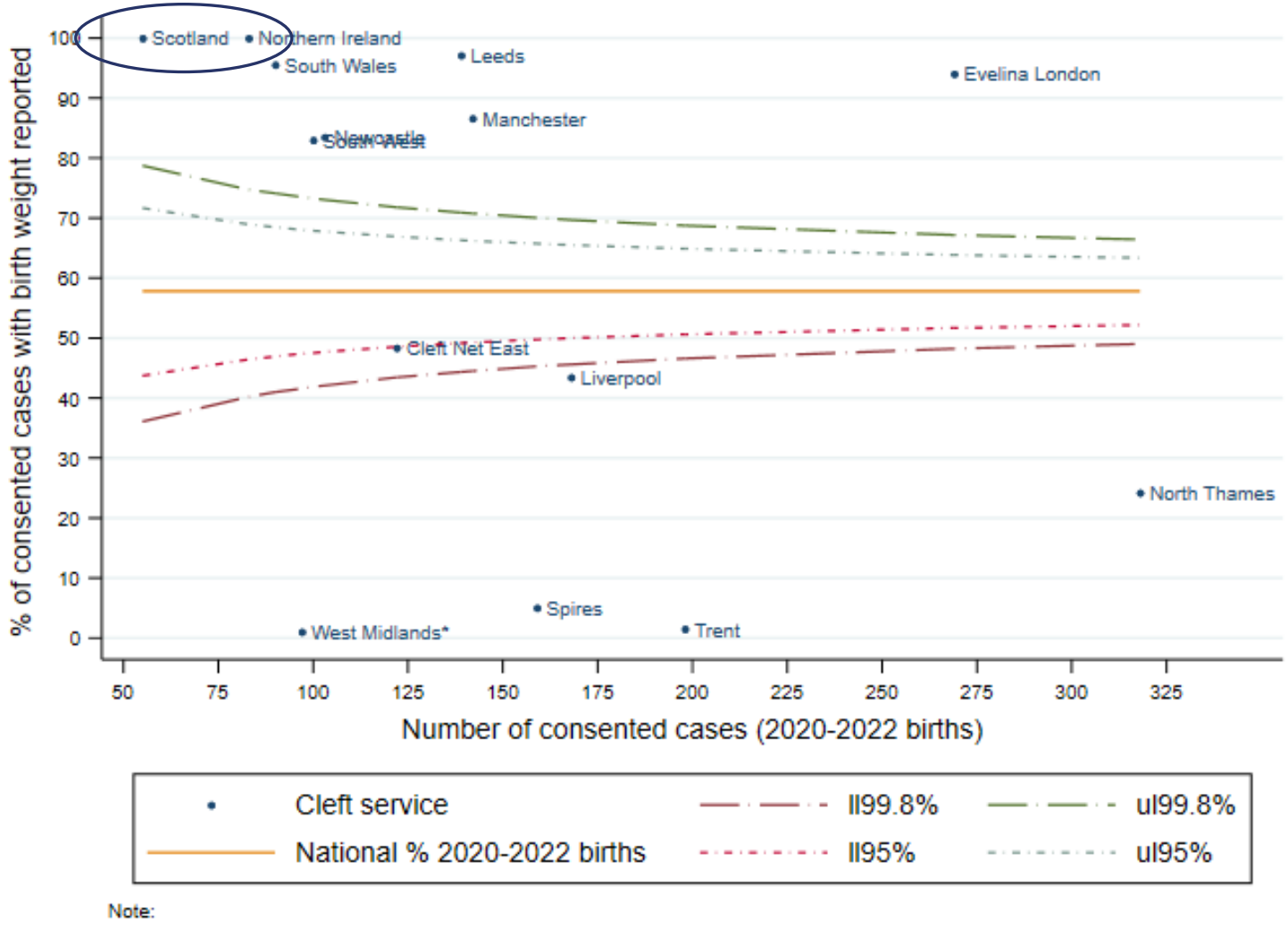
- Average: 21% (range: 6%-48%) of CPO cases
- Variability between services
- X-axis labelling error identified in report (showed 2014-16 cases) – now corrected.

Gestational age: Data completeness



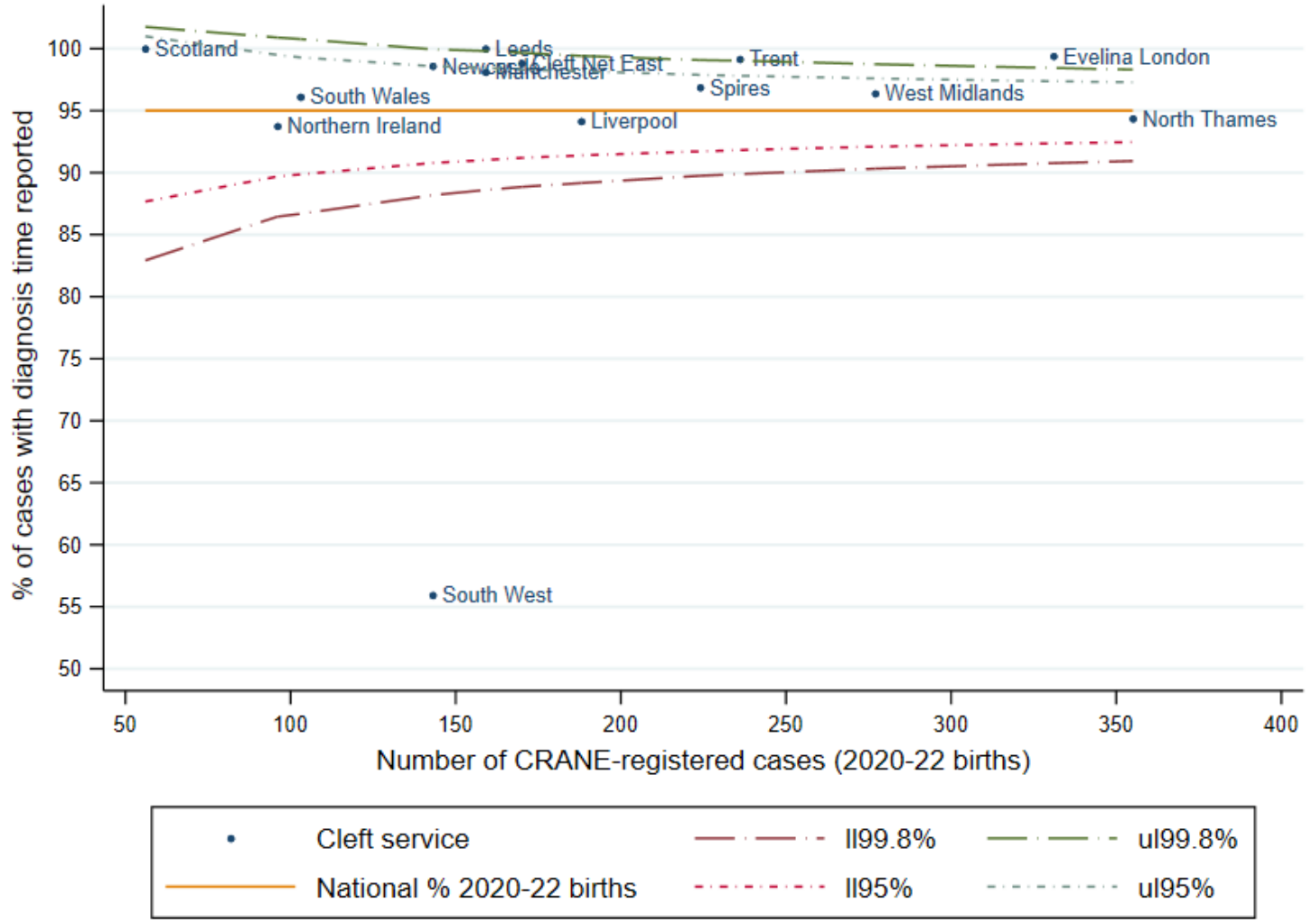
- Consented cases only
- Extreme variability in reporting between services
- Range: 1%-100%
- Most services outside of funnel
- Are maternity services sharing this information?
- Scotland will share how they achieved 100% rate

Birthweight: Data completeness



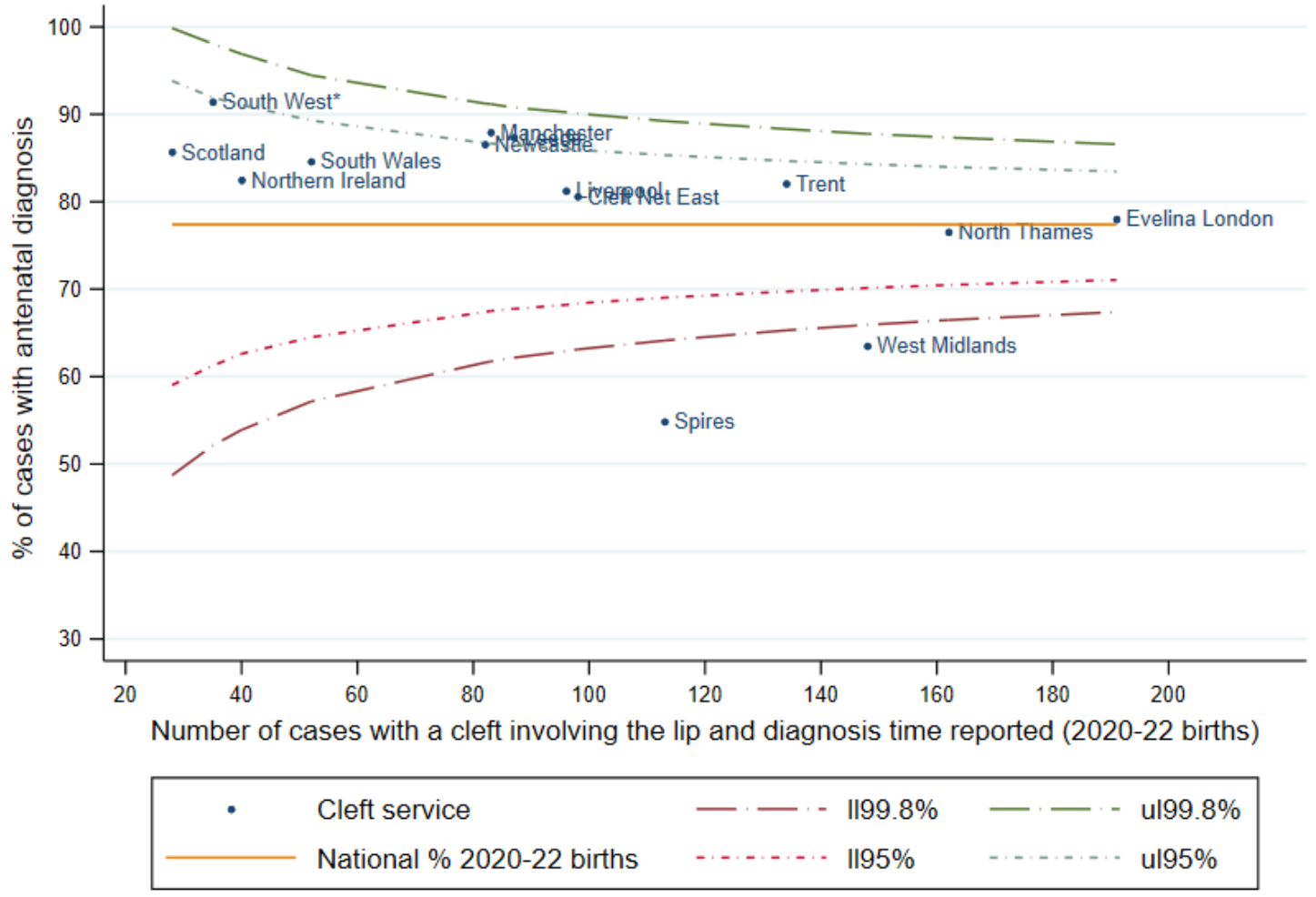
- Almost identical plot for birthweight, with all services in the same position.
- Range: 1%-100% of consented cases
- Most services outside of funnel

Diagnosis time: data completeness



- Majority of services reported diagnosis time for >94% of cases.
- Need to determine negative outliers for data completion before generating outcome funnel.

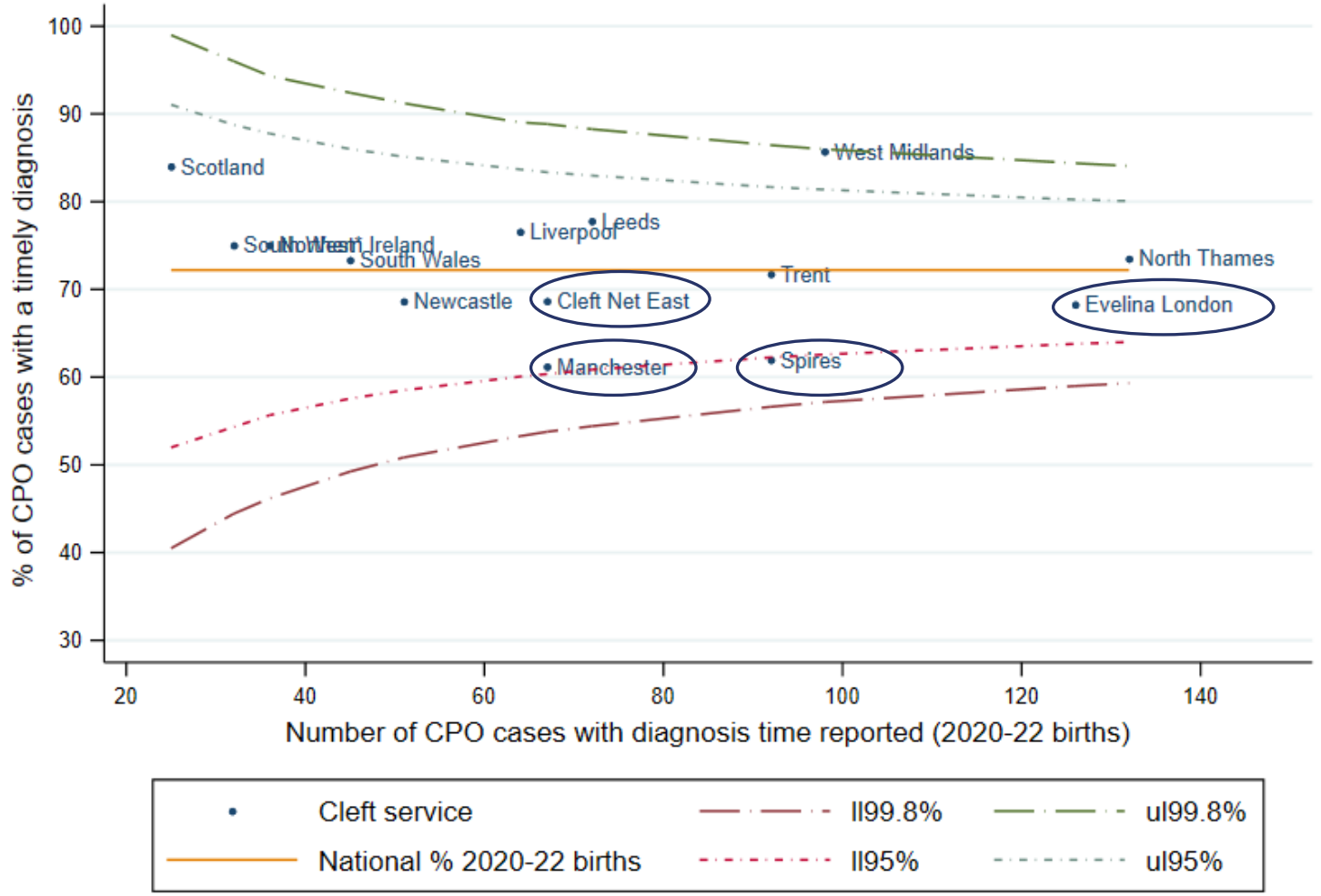
Antenatal diagnosis for clefts involving the lip



Note 1: Data from South West were not used to create funnel plot due to poor data completeness rate.

- Reflects maternity care
- Range: 55%-91%
- For majority of services, >80% of their cases involving the lip received antenatal diagnosis.
- This information used to be illustrated with bar charts.
- Funnel shows negative outliers.
- Information can be used to facilitate discussion with referring maternity services.

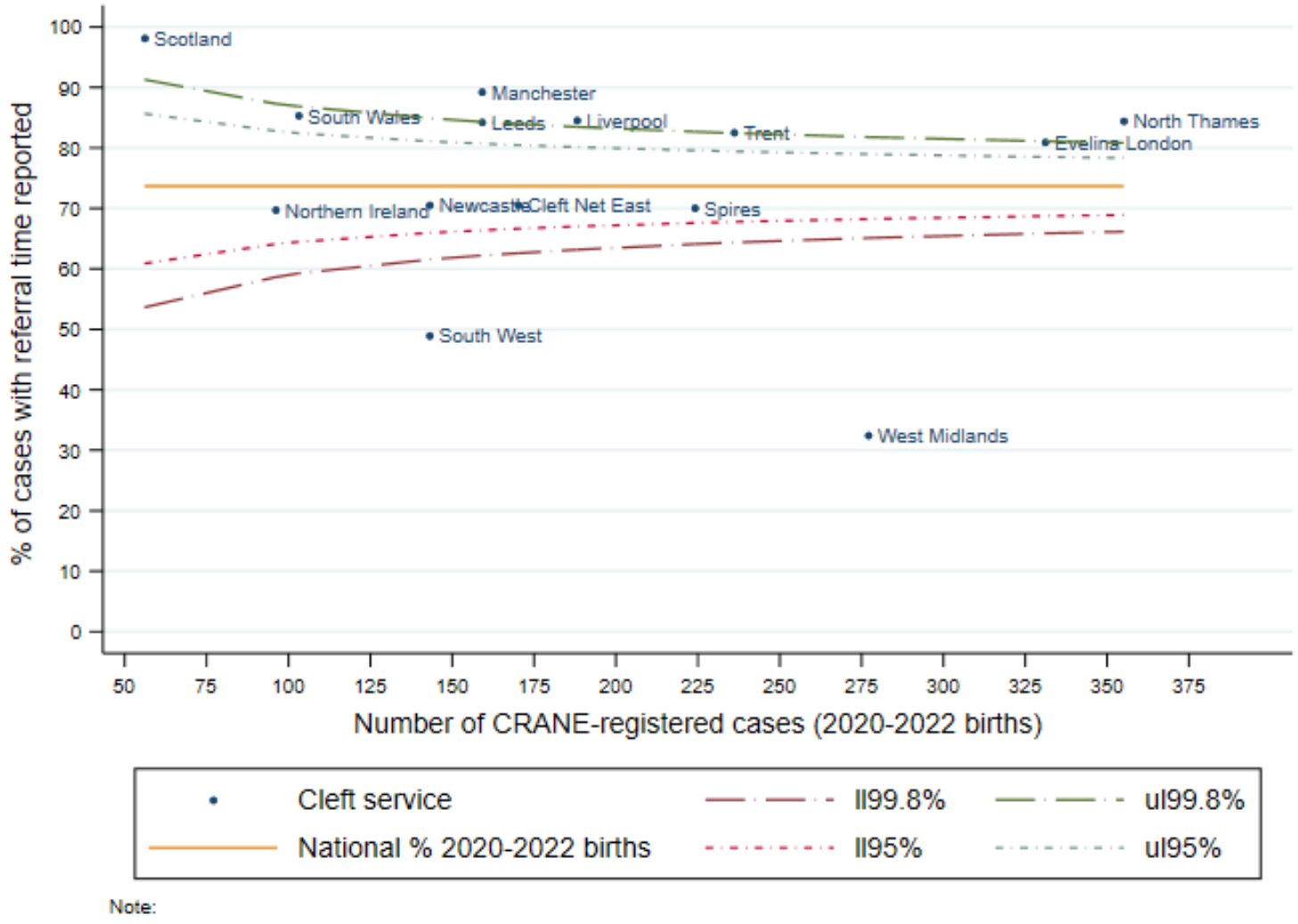
Timely diagnosis (before/at birth) of CPO (excluding SMCP)



Note 1: Data from South West were not used to create funnel plot due to poor data completeness rate.

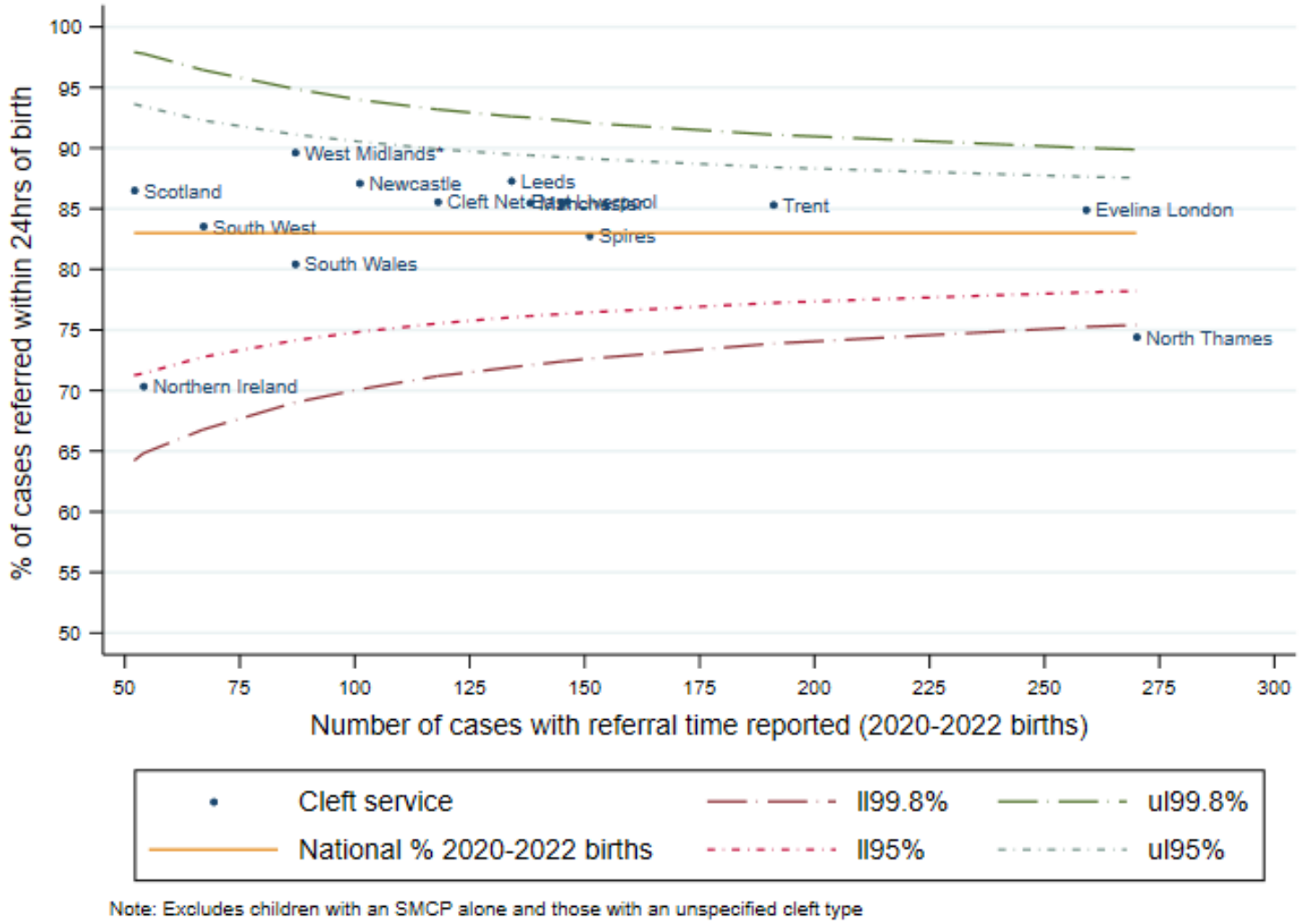
- Reflects maternity care
- Within 24hrs of birth
- Range: 61%-86%
- Variability but no outliers.
- Position changes when including diagnoses <72hrs
  - Mean:84% (78%-92%)
- Timing of newborn check?
- Information could be used to facilitate discussion with referring maternity services.

Referral time: data completeness



- A lot of variability.
- Range: 33%-98%
- 7 outliers
- Need to determine negative outliers before generating outcome funnel.
- What are the barriers to data submission?
  - West Midlands will share challenges.

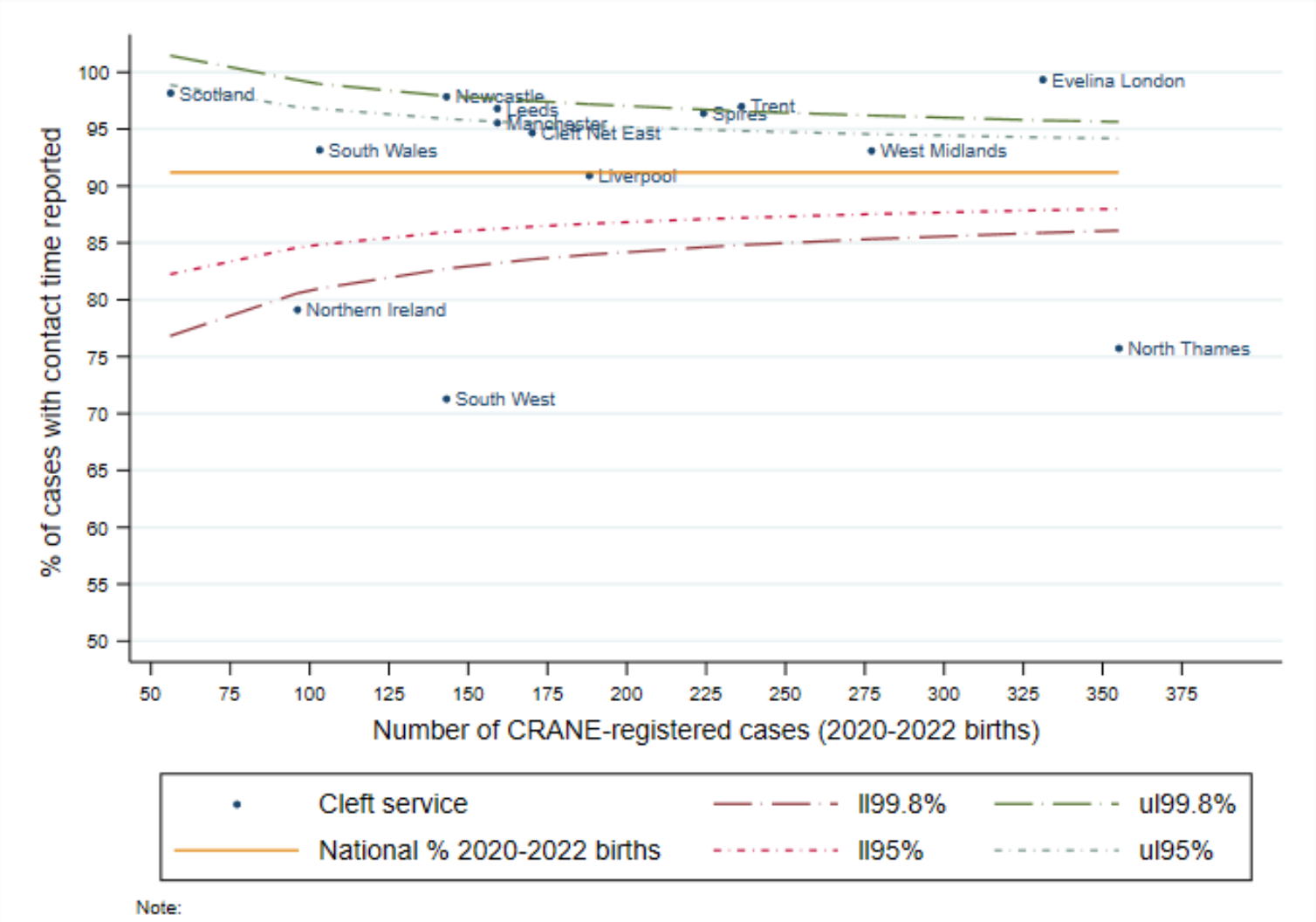
Referral within 24hrs of birth (excludes SMCP & unspecified cleft types)



Note: Excludes children with an SMCP alone and those with an unspecified cleft type

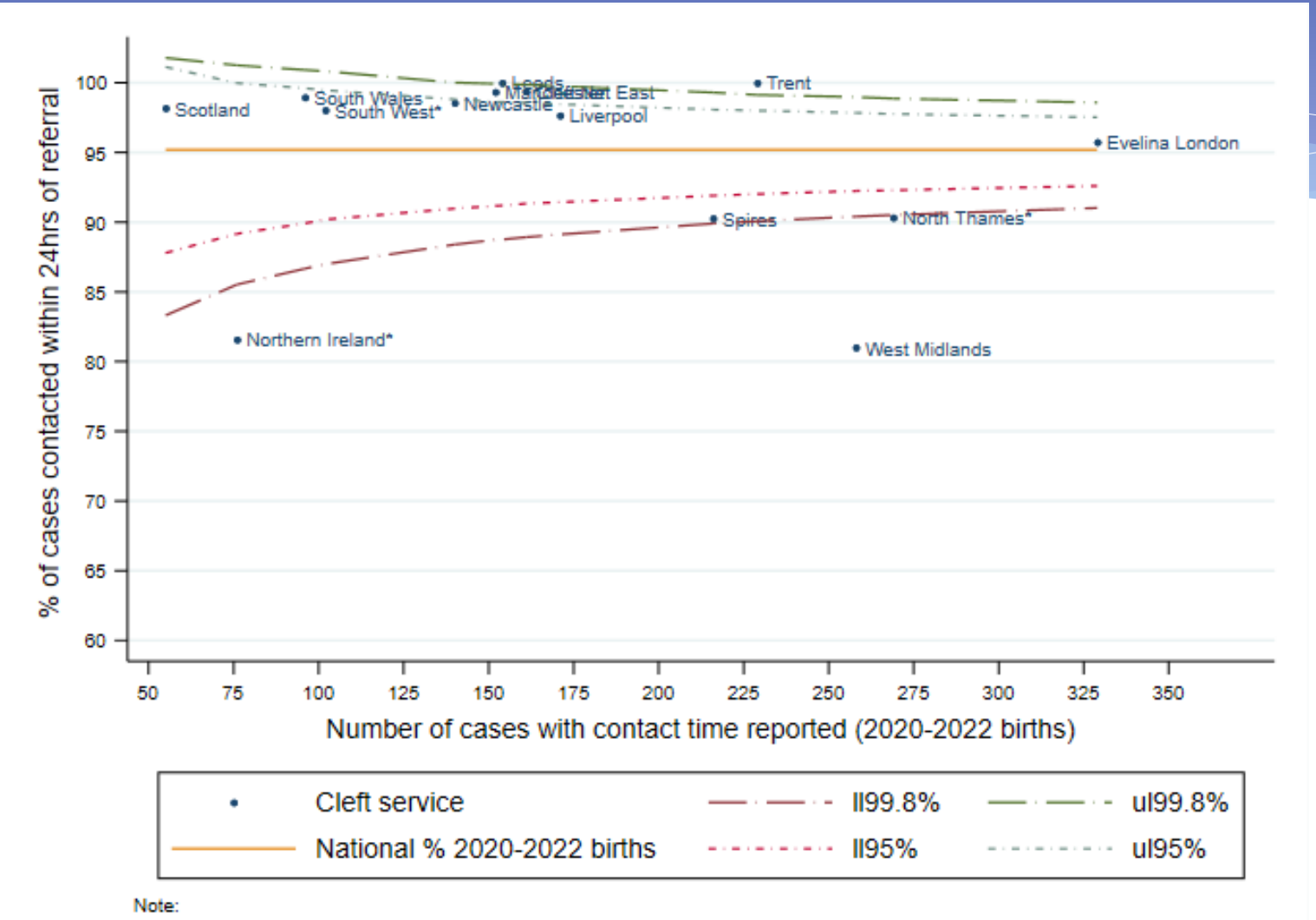
- SMCP & unspecified cleft types excluded due to differences in diagnosis time.
- Reflects maternity care
- 2% lower than 2018-20 births
- Range: 70%-90%
- 1 outlier.
- Information could be used to facilitate discussion with referring maternity services.

Contact time between cleft service & family: data completeness



- Better data completion vs referral time.
- Range: 71%-99%
- 5 outliers
- Need to determine negative outliers before generating outcome funnel.
- What are the barriers to data submission?

Contact with family within 24hrs of referral



- Mean: 94% (no change since 2018-20 births)
- Range: 81%-100%
- Majority make contact with >95% of families within 24hrs
- Rates varied by cleft type ($p<0.001$)
  - SMCP: 74%
  - CP: 93%
  - Other types: >95%

Supplementary tables: alert/outlier status

Cleft Registry and Audit NEtwork Database

Part of the Clinical Effectiveness Unit, of the Royal College of Surgeons of England

2023 Annual Report: Responses to outlier process

Results of the audit in England, Wales, Northern Ireland and Scotland for children born with a cleft between January 2000 and December 2022

On behalf of the Cleft Development Group

TOC

Cleft service alert and outlier status for data submitted to the CRANE Database by 4 July 2023 (2014-2016 births - Annual Report 2023)

		DATA COMPLETENESS														OUTCOME																	
	Cleft Service	Consent verification		Child growth (reporting)		Dental health (reporting)		Facial growth (Reporting)		Speech (Reporting)		TIM - Psychology (Reporting)		SDQ - Psychology (Reporting)		Child growth (Healthy BMI)		Dental health (dmft>0)		Dental health (dmft>5)		Facial growth (good scores)		Speech (standard 1)		Speech (standard 2A)		Speech (standard					
		Alert	Outlier	Alert	Outlier	Alert	Outlier	Alert	Outlier	Alert	Outlier	Alert	Outlier	Alert	Outlier	Alert	Outlier	Alert	Outlier	Alert	Outlier	Alert	Outlier	Alert	Outlier	Alert	Outlier	Alert	Outl				
	Newcastle		+ve*		+ve*		+ve*			+ve*	Alert x2		+ve		+ve*												+ve					
	Leeds		+ve*				Alert x2																	-ve		-ve		-ve					
	Liverpool					-ve*						+ve																					
	Manchester				+ve*								+ve																				
	Trent								+ve*		+ve*		-ve		-ve*												+ve*	Alert x2					
	West Midlands		-ve		-ve*		+ve*		-ve		-ve		-ve		-ve*	NP	NP		+ve	+ve		NP	NP									
	Cleft Net East				+ve*		+ve				-ve*				+ve*					-ve				-ve				-ve				
	North Thames	+ve			+ve		-ve*						+ve											-ve				-ve				
	Spires	-ve			-ve		+ve*						+ve		+ve*			+ve*	Alert x2	+ve												
	South Wales				+ve*		+ve*				+ve		+ve		+ve*																		
	South West				-ve*		-ve*		-ve*		-ve		-ve		-ve	NP	NP					NP	NP									
	Evelina London				-ve*		-ve*				-ve			-ve													-ve*	Alert x2					
	Northern Ireland						+ve*							+ve								-ve											
	Scotland	NP	NP	NP	NP	NP	NP	NP	NP	NP	NP	NP	NP	NP	NP	NP	NP	NP	NP	NP	NP	NP	NP	NP	NP	NP	NP	NP	NP	NP	NP	NP	NP

With the exception of consent verification, calculations are performed for consented children only. Children dying before 5 years and those with a submucous cleft palate are excluded.

Key	
+ve	Positive alert or outlier
+ve*	Positive alert or outlier for two consecutive reporting periods (2012-2014 births and 2014-2016 births)
-ve	Negative alert or outlier
-ve*	Negative alert or outlier for two consecutive reporting periods (2012-2014 births and 2014-2016 births)
NP	Not plotted due to insufficient children with data (<10)
Y	Alert or outlier
	Negative outlier for consent verification. Review other results with caution

Provided in a workbook alongside the Annual Report

Learning from good practice and challenges relating to data submissions

Local action plan

https://www.crane-database.org.uk/resources/crane-local-action-plan-2023/

To drive quality improvement

Local Action Plan for responding to CRANE 2023 Annual Report recommendations

The Cleft Service 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, Northern Ireland and Scotland with the congenital abnormality of cleft lip and/or palate.
Cleft Service / 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 2023 Annual Report'** here:
https://www.crane-database.org.uk/reports/crane-database-2023-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

Speakers

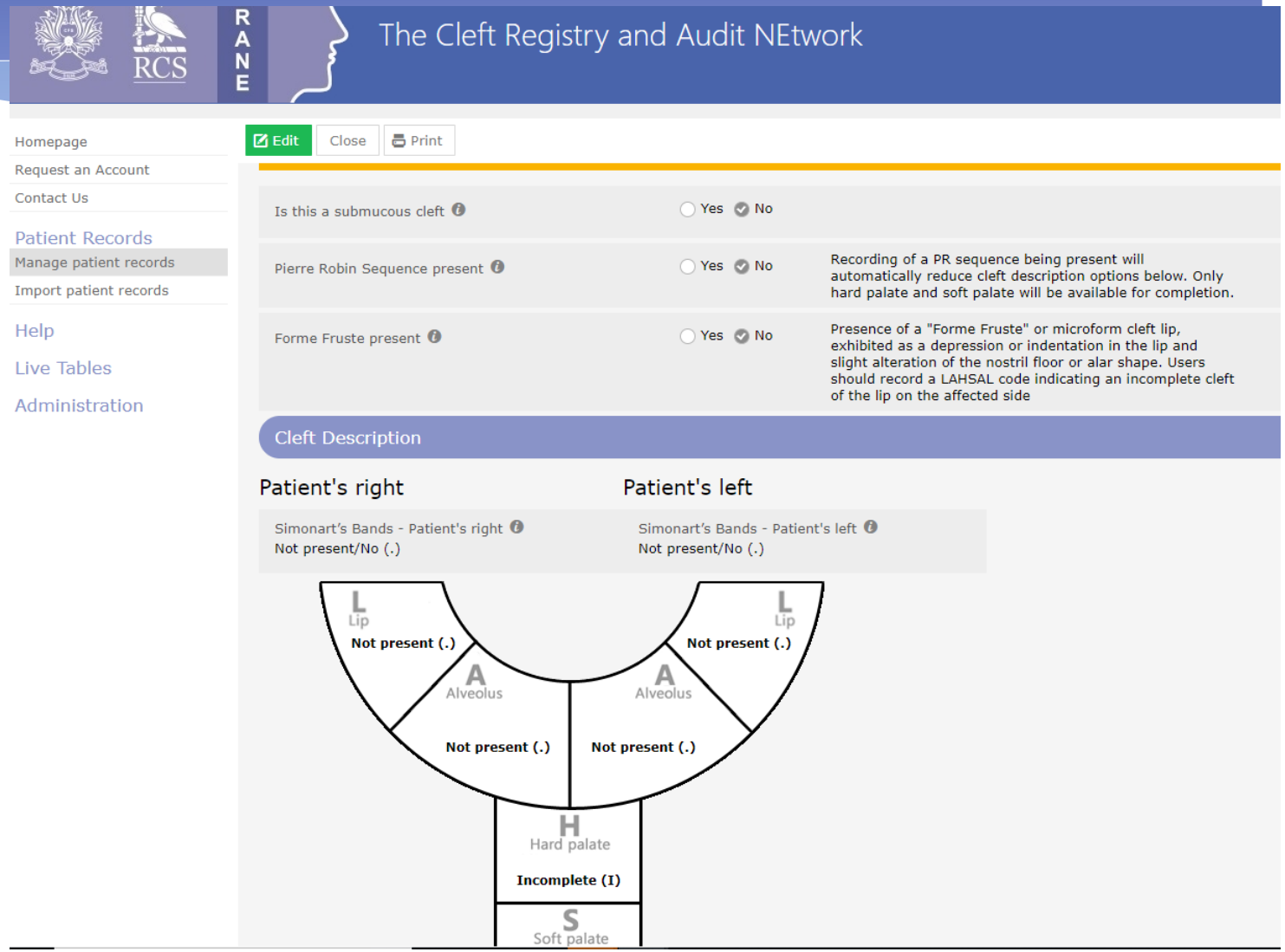
1. **Peri Codling** (Cleft Net East):
   * Rapidly turning around a low consent verification rate
   * Reflections on low reported rates of Robin Sequence
2. **Helen Extence** (South Wales):
   * Reflections on high reported rates of Robin Sequence
   * Maintaining excellence in data completeness
3. **Lyndsay Kirk** (Scotland): Achieving 100% data completeness for gestational age and birthweight
4. **Natalie Matthews** (West Midlands): Challenges in submitting data to CRANE and plans to overcome these in future

Question and Answer session

Database Developments

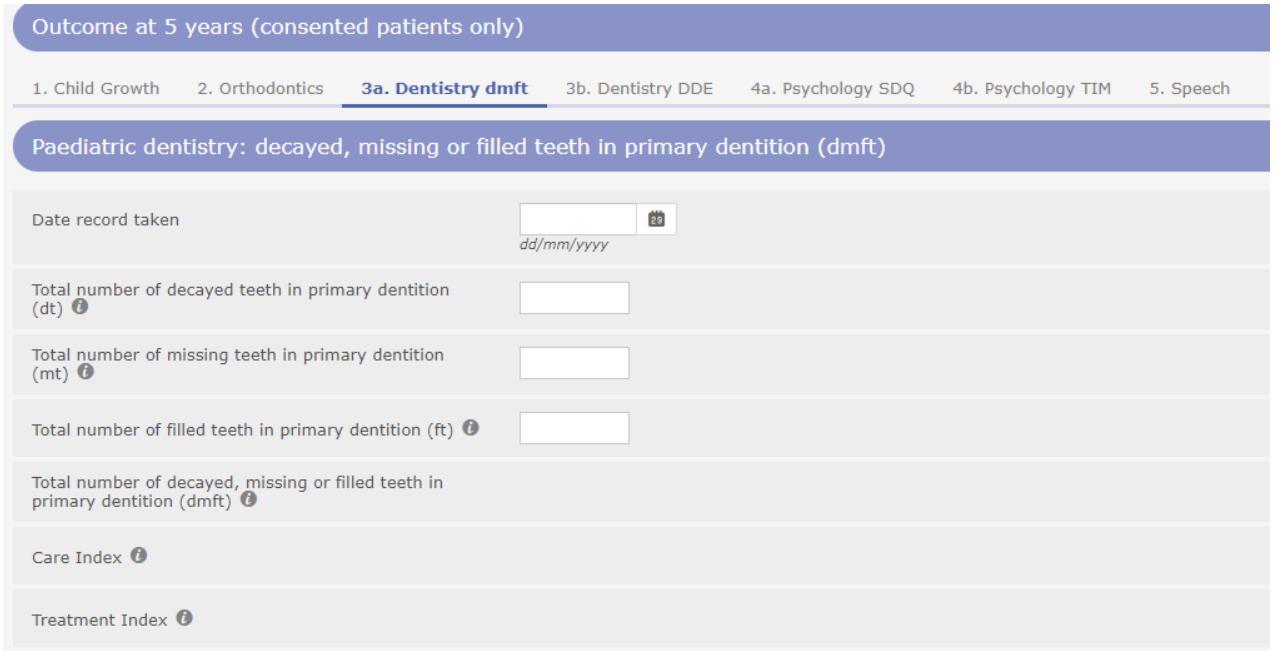
Submucous cleft palate

* LAHSAL code now independent from SMCP box.
* Previously, LAHSAL code would change to little ‘s’ if SMCP was ticked.
* Allows for improved accuracy of cleft type, e.g. CL+SMCP



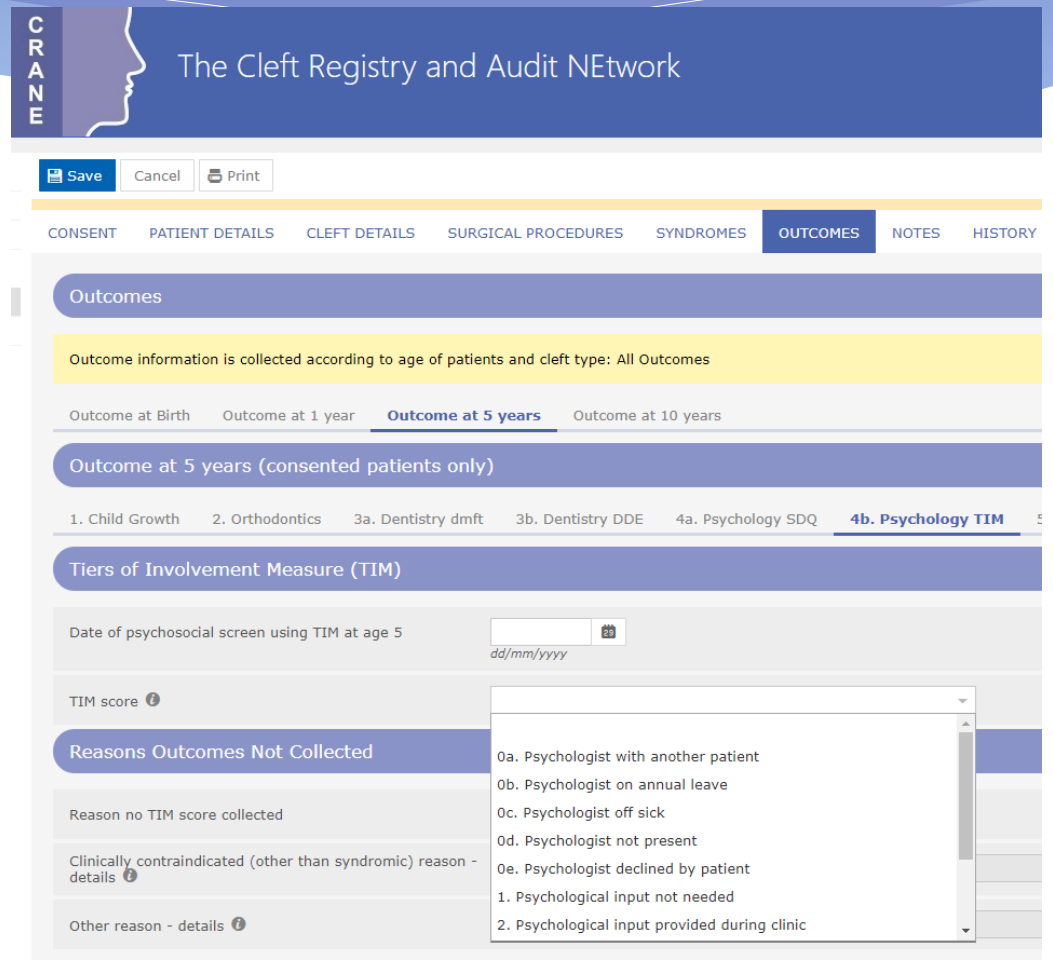
Total dmft score

* Total dmft score is now automatically calculated based on the individual element scores (dt+mt+ft)
  * This will limit data inconsistencies and improve the accuracy of dmft data.



Psychology

* TIM score scale has been updated to collapse subscores of 1 (seen by psychologist but no input required) and 2 (psychological input provided in clinic).
* TIM score now has it's own 'reason outcome not collected'
* SDQ scores no longer collected for children born after 2017.



Database development: Next steps

- New psychology outcome (to replace SDQ) being considered by CEN
- New audiology outcomes being considered by CEN
- Analyses of Newborn Hearing Screening Programme (NHSP) data linked to CRANE

Quality Improvement Resources

Next meeting

7 February 2023 from 10:30

‘CRANE data Q & A’

For anyone who submits data

Improving your data

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

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

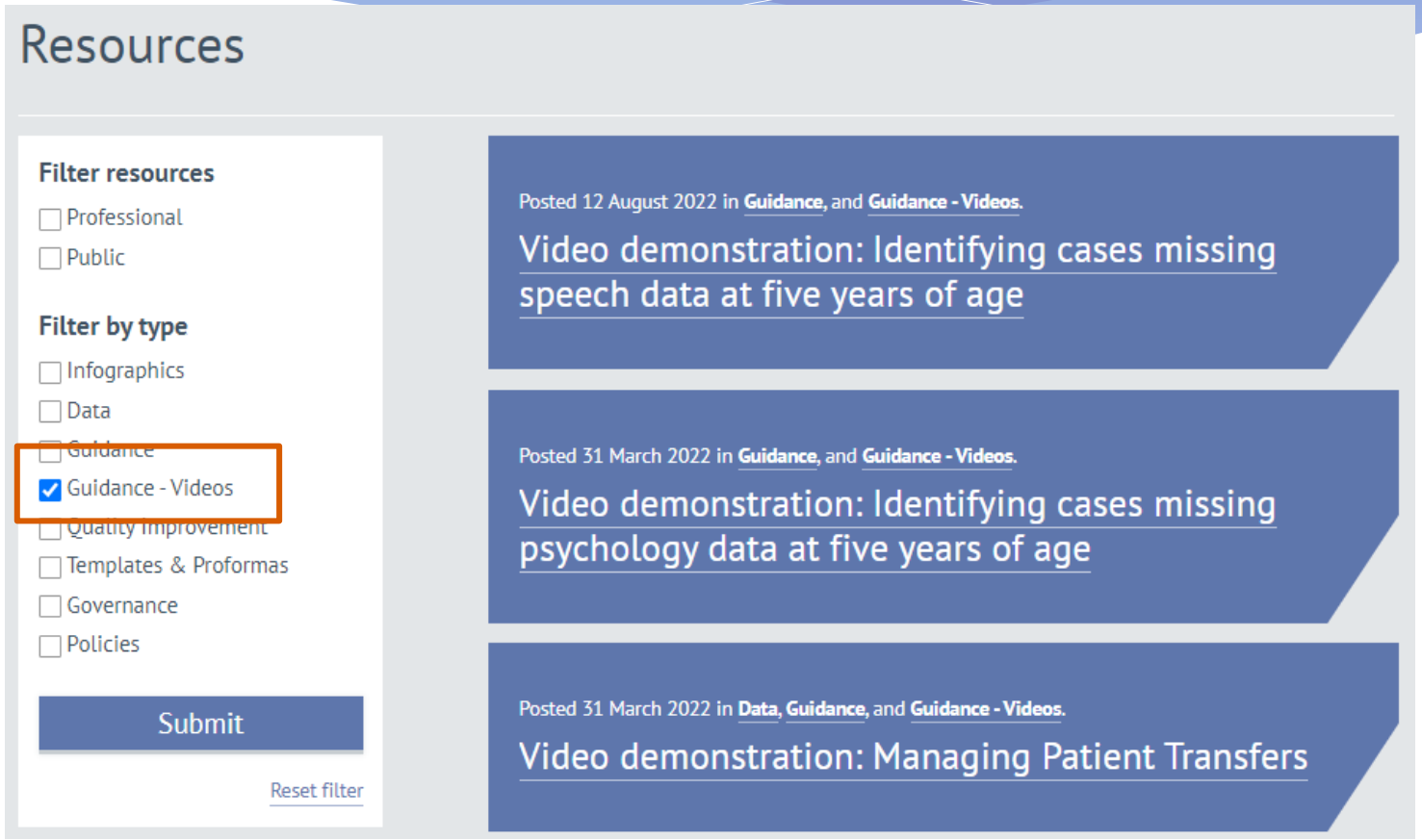
https://www.crane-database.org.uk/resources/

11 x Guides

Improving your data

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

6 x Video demonstrations

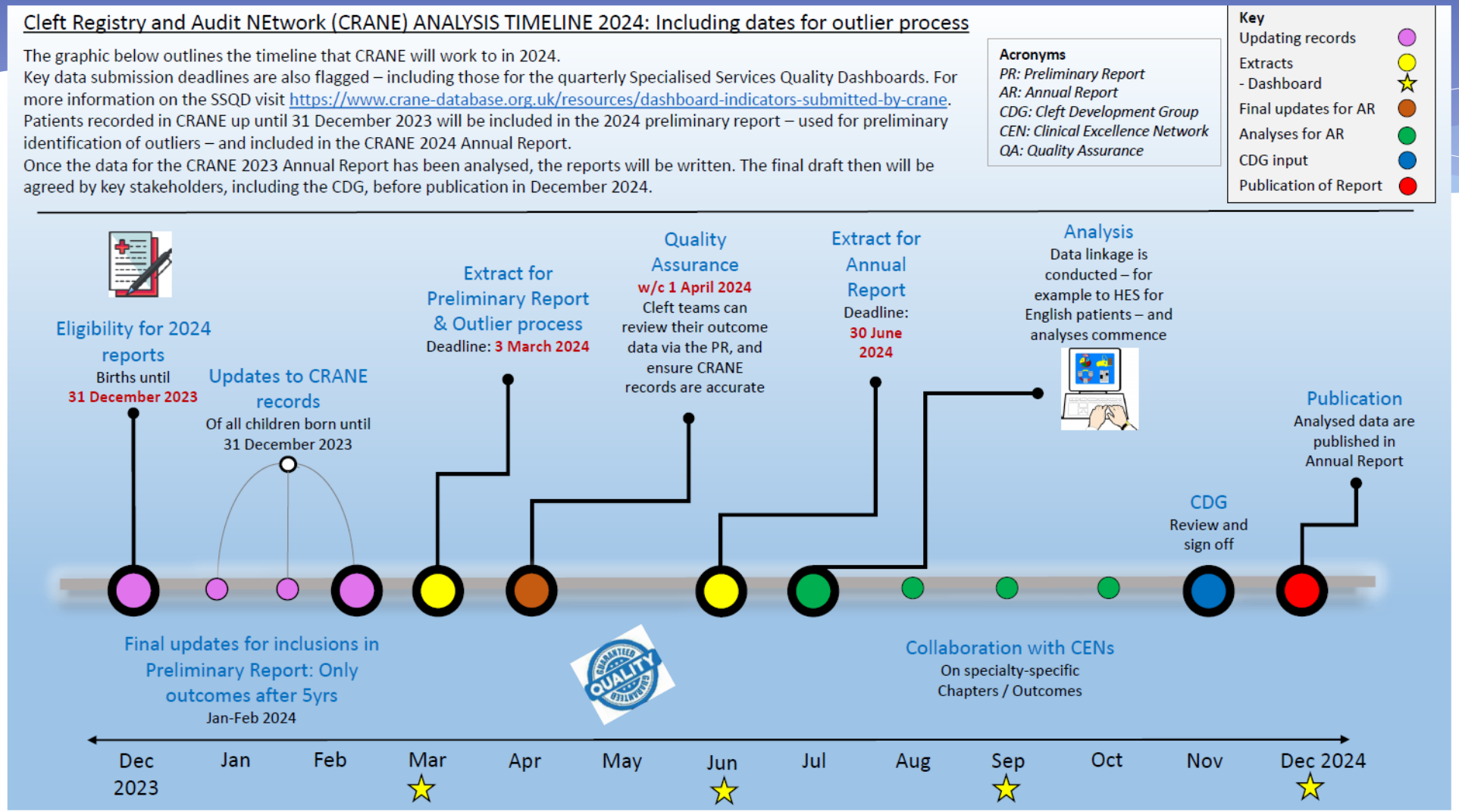


Improving your data

- Workbooks will be shared with each service listing CRANE IDs whose records need updating:
  - Cleft type issues, missing postcode and/or NHS number, etc.
- Correcting these errors will improve the accuracy of the data used for future reporting and will enhance our ability to link with other datasets.

Important Dates

Timeline for 2024



https://www.crane-database.org.uk/resources/data-collection-milestones-for-2024/

Data submission deadlines

CRANE deadlines:

- Sunday 3 March 2024 – Preliminary report
  - Registrations for 2021 to 2023 births
  - 5-year outcomes for 2015 to 2017 births
- Sunday 30 June 2024 – Annual report

Dashboard deadlines:

- Friday 8 March 2024 - Q3 2023/24
- Friday 14 June 2024 – Q4 2023/24

Use our resources to check your data and contact crane@rcseng.ac.uk with queries – but do not incl. P.I.D.

Alert

- Please remember when contacting CRANE about a patient
  - **Only use CRANE ID**
  - Never send patient identifiable information to our contact us page or via email:
    - NAME
    - DOB
    - HOSPITAL NUMBER

Thank you

crane@rcseng.ac.uk

@CRANE_News

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