

**CLEFT REGISTRY & AUDIT NETWORK**

## **CRANE Database**

### **2018 Annual Report**

Results of the audit in England, Wales and Northern Ireland  
for children born between January 2000 and December 2017

On behalf of the Cleft Development Group

[www.crane-database.org.uk](http://www.crane-database.org.uk)



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Version (2) was released on 5 August 2019: Including corrections to Table 3, in the Decayed Missing and Filled Teeth Section on page 25, and Figure 9, in the Outpatient Hospital Appointments Section on page 51.

Version (2.1) was released on 29 August 2019: Including a correction to the Executive Summary on page 10.

This version (2.2) was released on 17 January 2020: Including a correction to Table 3 on the relationship between dental health and deprivation at 5 years of age (Chapter 3) on pages 25 to 27.

# Contents

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Acknowledgements.....	5
Abbreviations.....	6
Glossary .....	8
Executive summary .....	10
<b>1. Introduction .....</b>	<b>11</b>
<b>2. Methods.....</b>	<b>12</b>
2.1. CRANE .....	12
2.2. Hospital Episode Statistics (HES) .....	15
<b>3. CRANE .....</b>	<b>18</b>
3.1. Registrations and contact with cleft teams .....	18
3.2. Characteristics of children born with a cleft lip and/or palate in 2017 .....	20
3.3. Timing of diagnosis .....	20
3.4. Overview of outcomes among children born with a cleft lip and/or palate .....	22
3.5. Decayed missing and filled teeth (dmft) at five years, 2004-2011 births.....	24
3.6. Five Year Old Index, 2004-2011 births.....	28
3.7. Relationship between facial growth and speech at five years, 2007-2011 births.....	30
3.8. Cleft Audit Protocol for Speech – Augmented (CAPS-A) ratings at five years, 2009-2011 births .	31
3.9. Psychology screening scores at five years, 2011 births .....	39
3.10. Patient (and Parent) Reported Experience Measure (PREM) Feasibility Study .....	46
<b>4. Outpatient hospital appointments at seven years of age in England.....</b>	<b>49</b>
4.1. Introduction .....	49
4.2. Outpatient hospital appointments according to type of cleft.....	49
4.3. Outpatient hospital appointments according to cleft Unit .....	53
4.4. Summary .....	58
<b>5. Development of CRANE Database and future directions.....</b>	<b>61</b>
5.1. Future development of the CRANE Database and website .....	61
5.2. Scotland .....	61
5.3. Outcome measures.....	61
5.4. Data sources and future analyses.....	61

5.5. Quality Dashboard .....	62
5.6. CRANE Communications .....	63
<b>6. Conclusions .....</b>	<b>64</b>
<b>Appendices .....</b>	<b>67</b>
Appendix 1: CRANE Project Team .....	67
Appendix 2: Governance and funding .....	68
Appendix 3: Regional Cleft Centres and Managed Clinical Network and their associated regions / units .....	69
Appendix 4: Diagnosis and Procedure Codes, Hospital Episode Statistics (HES) .....	70
Appendix 5: Five Year Old Index scores detail.....	71
Appendix 6: Cleft Audit Protocol for Speech: Ratings for individual 16 CAPS-A parameters .....	72
Appendix 7: Cleft Audit Protocol for Speech: Speech Outcome Standards .....	73
Appendix 8: Psychology screening scores detail .....	74
Appendix 9: Outpatient hospital appointments: Tables of data for figures in Chapter 4.....	75

# Tables and Figures

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<b>Table 1.</b> Number (%) of CRANE-registered children born between 2013 and 2017 with a cleft palate, according to the timing of diagnosis and region / unit. ....	21
<b>Table 2.</b> Number (%) of CRANE-registered children born between 2013 and 2017 with a cleft palate, according to complete / incomplete hard and soft palates. ....	22
<b>Table 3.</b> CRANE-registered consented children born between 2004 and 2011 with a cleft lip and/or palate, according to cleft type and deprivation, and their average treatment index and care index at age five years. ....	25
<b>Figure 1.</b> Funnel plot of five-year olds (born between 2004 and 2011) with poor Five Year Old Index scores according to the number of children at each region / unit with index scores. ....	29
<b>Table 4.</b> Number (%) of CRANE-registered <sup>a</sup> consented children born between 2007 and 2011 <sup>b</sup> , with good or poor Five Year Old Index scores at five years of age, by those achieving/not achieving normal speech. ....	30
<b>Table 5.</b> Number (%) of CRANE-registered <sup>a</sup> consented children born with a cleft palate in 2009-2011, with speech outcome data or reasons this outcome was not collected at five years of age, according to region / unit. ....	32
<b>Figure 2.</b> Funnel plot of five-year olds (born 2009-2011) with ratings suggesting speech within the normal range, according to the number of children at each region / unit with CAPS-A ratings. ....	34
<b>Figure 3.</b> Funnel plot of five-year olds (born 2009-2011) with ratings suggesting no structurally related speech difficulties, according to the number of children at each region / unit with CAPS-A ratings. ....	36
<b>Figure 4.</b> Funnel plot of five-year olds (born 2009-2011) with ratings suggesting no cleft-related articulation difficulties, according to the number of children at each region / unit with CAPS-A ratings. ....	37
<b>Figure 5.</b> Proportion of CRANE-registered consented children born with a cleft lip or palate (2011), according to the Tiers of Involvement Measure (TIM) levels of psychological involvement / input received. ....	41
<b>Table 6.</b> Number (%) of CRANE-registered consented children born with a cleft lip or palate (2011), according to Tiers of Involvement Measure (TIM) levels and cleft type. ....	42
<b>Figure 6.</b> Proportion of CRANE-registered consented girls and boys born with a cleft lip or palate (2011), according to the Tiers of Involvement Measure (TIM) levels of psychological involvement / input received. ....	43
<b>Table 7.</b> Number (%) of CRANE-registered consented children born with a cleft lip or palate (2011), according to grouped Tiers of Involvement Measure (TIM) levels and SDQ Total difficulties scale bands. ....	44
<b>Figure 7.</b> Proportion of responses to each CHI-ESQ item, according to each available answer category. ....	47

<b>Figure 8.</b> Percentage of children with a non-syndromic cleft according to cleft type and how many hospital outpatient appointments they attended during school Year 2.....	50
<b>Figure 9.</b> Percentage of children with a non-syndromic cleft seeing each specialty in hospital outpatient appointments during school Year 2, according to cleft type .....	51
<b>Figure 10.</b> Proportion of all hospital appointments attended by non-syndromic children during school Year 2, according to cleft type and the various treating specialties* .....	52
<b>Figure 11.</b> Percentage of annual hospital appointments attended by children with a non-syndromic cleft during year 2 of school according to calendar month.....	53
<b>Figure 12.</b> Percentage of children with a non-syndromic cleft according to cleft Unit and how many hospital outpatient appointments they attended during school Year 2.....	54
<b>Figure 13.</b> Funnel plot showing percentage of children with a non-syndromic cleft within each unit who had 0 outpatient appointments during Year 2 of school* .....	55
<b>Figure 14.</b> Funnel plot showing percentage of children with a non-syndromic cleft within each unit who had at least one appointment under Ear, nose or throat or Audiology during Year 2 of school..	56
<b>Figure 15.</b> Funnel plot showing percentage of children with a non-syndromic cleft within each unit who had at least one appointment under cleft-related surgery during Year 2 of school.....	57
<b>Figure 16.</b> Funnel plot showing percentage of children with a non-syndromic cleft who had at least one appointment under Dental during Year 2 of school, according to the number of children registered within each unit. ....	58
<b>Figure 17.</b> Proportion of all hospital appointments attended by non-syndromic children during school Year 2, according to cleft Unit and the various treating specialties* .....	59

# Acknowledgements

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We would like to thank the members of the Cleft Units for their continued efforts to liaise with the Cleft Registry & Audit NEtwork (CRANE) Database – the national cleft database for England, Wales and Northern Ireland – over the last year.

We would also like to extend our thanks to the following people:

- members of the Cleft Development Group for their advice and contributions in writing this report;
- Vanessa Hammond for her contribution in drafting the five-year psychology outcome section of this report , which is the first time CRANE has reported on this;
- Lorraine Britton for her contribution towards the interpretation of the five-year speech outcome data; and
- Jackie Smallridge for her contribution towards the interpretation of the decayed, missing and filled teeth data at five years.

Hospital Episode Statistics (HES) data have been re-used with the permission of The Health and Social Care Information Centre. All rights reserved. Copyright © 2013.

This work was funded by the National Specialised Commissioning Group for England, the Wales Specialised Health Services Committee, and the Northern Ireland Specialist Services Commissioning Team; and was carried out by the project team of the CRANE Database, which is overseen by the UK NHS Cleft Development Group (CDG)<sup>1</sup>.

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<sup>1</sup> [Appendices 1 and 2](#) provide detail on the project team, and the project's Governance and funding arrangements. [The Cleft Development Group](#) CRANE web page provides detail on the CDG Membership and Terms of Reference.

# Abbreviations

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<b>BCLP</b>	Bilateral cleft lip and palate
<b>CAPS-A</b>	Cleft Audit Protocol for Speech—Augmented
<b>CDG</b>	Cleft Development Group
<b>CEN</b>	Clinical Excellence Network – previously referred to as Special Interest Group (SIG)
<b>CSCs</b>	Cleft Speech Characteristics
<b>CFSGBI</b>	Craniofacial Society of Great Britain and Ireland
<b>CI</b>	Confidence interval
<b>CL</b>	Cleft lip only
<b>CLEFTSiS</b>	The National Management Clinical Network for Cleft Service in Scotland
<b>CP</b>	Cleft palate only
<b>CSAG</b>	Clinical Standards Advisory Group
<b>CRG</b>	Clinical Reference Group
<b>Dmft</b>	Decayed, missing and filled teeth
<b>DfE</b>	Department for Education
<b>DoH</b>	Department of Health
<b>ENT</b>	Ear, nose and throat
<b>ESQ</b>	Experience of Service Questionnaire
<b>GOSH</b>	Great Ormond Street Hospital
<b>FFT</b>	Friends and Family Test
<b>HES</b>	Hospital Episode Statistics
<b>ICD-10</b>	International Classification of Disease 10th Revision
<b>KS1</b>	Key Stage 1 – educational assessment
<b>MCN</b>	Managed Clinical Network
<b>MDT</b>	Multi-Disciplinary Team
<b>NPD</b>	National Pupil Database
<b>OPCS-4</b>	Classification of Surgical Operations and Procedures 4th Revision
<b>PEDW</b>	Patient Episode Data Wales
<b>PREM</b>	Patient Reported Experience Measure
<b>RCPCH</b>	Royal College of Paediatrics and Child Health
<b>SCG</b>	Specialised Commissioning Group
<b>SD</b>	Standard deviation
<b>SDQ</b>	Strengths and Difficulties Questionnaire
<b>SLT</b>	Speech and language therapy
<b>TIM</b>	Tiers of Involvement Measure



<b>UCLP</b>	Unilateral cleft lip and plate
<b>VTCT</b>	Vocational Training Charitable Trust
<b>WHO</b>	World Health Organization

# Glossary

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<b>Administrative Unit</b>	A hospital that provides cleft surgery and submits data to the CRANE Database, sometimes as part of a wider cleft centre or network.
<b>Alveolus / alveolar</b>	The part of the jaw that supports the teeth and contains the tooth sockets.
<b>Caries (dental)</b>	Dental caries are also known as tooth decay / dental decay or a cavity.
<b>Cleft</b>	A failure of tissues to join during development.
<b>Cleft Development Group (CDG)</b>	NHS National group representing all stakeholders in cleft care that is responsible for the CRANE Database as well as oversight and guidance on all aspects of the delivery of reorganised cleft care.
<b>Cleft surgeon</b>	A surgeon undertaking cleft repair surgery in a region / unit.
<b>Clinical Standards Advisory Group (CSAG)</b>	A group established in 1991 to act as an independent source of expert advice on standards of clinical care for, and access to and availability of services to, NHS patients.
<b>Confidentiality Advisory Group (CAG)</b>	An independent statutory body established to promote, improve and monitor information governance in health and adult social care. <a href="http://www.hra.nhs.uk/research-community/applying-for-approvals/confidentiality-advisory-group-cag/">http://www.hra.nhs.uk/research-community/applying-for-approvals/confidentiality-advisory-group-cag/</a>
<b>Craniofacial anomalies</b>	A diverse group of deformities in the growth of the head and facial bones.
<b>Craniofacial Society of Great Britain and Ireland (CFSGBI)</b>	An inter-specialty group set up to study cleft lip and palate and other craniofacial anomalies. <a href="http://www.cfsgb.org.uk">www.cfsgb.org.uk</a>
<b>Funnel Plot</b>	<p>A graph that identifies regions / units which are outliers, where the local situation might require closer inspection – either because an area is doing well or because there is some indication that it is performing poorly. In this report:</p> <ul style="list-style-type: none"><li>• Each point on the funnel plot represents a region / unit.</li><li>• Each funnel plot is for one outcome, with its values shown on the vertical/Y axis.</li><li>• The size of the regions' /units' cohort is shown on the horizontal or X axis.</li><li>• The benchmark value is shown as a horizontal line through the centre of the graph.</li></ul> <p>The graph shows two funnels that lie on either side of the benchmark and are called the control limits – similar to confidence intervals.</p> <ul style="list-style-type: none"><li>• The inner lines show 2 standard deviations or 95% control limits. The outer lines represent 3 standard deviations or 99.8% control limits.</li><li>• The funnel shape is formed because the control limits get narrower as the population size increases.</li></ul> <p>The outer funnel is used to decide if an area is significantly different to the benchmark with 99.8% confidence. If a point lies within the funnel then we conclude that it is not significantly different to the benchmark. If it falls outside the funnel then we can say the value is significantly 'better' or significantly 'worse' than the benchmark, depending on the direction of the indicator/outcome.</p>

Funnel Plot Source: David Spiegelhalter, Medical Research Council  
Biostatistics Unit -  
<http://www.erpho.org.uk/Download/Public/6990/1/INPHO%204%20Quantifying%20performance.pdf>

**Hospital Episode Statistics (HES)**

A national database containing records on all admissions to NHS hospitals in England.

**Key Stage 1 (KS1)**

An assessment of children's educational attainment across five subject areas at seven years of age.

**LAHSAL**

A code used to classify clefts. Each letter (LAHSAL) relates to one of the six parts of the mouth that can be affected by a cleft.

**Managed Clinical Network (MCN)**

A formally organised network of clinicians.

**National Pupil Database (NPD)**

A database containing records on all pupils in England as they progress through primary and secondary education.

**Patient Episode Data Wales (PEDW)**

A national database containing records on all admissions to hospitals in Wales.

**Submucous Cleft Palate**

The term submucous refers to the fact that the cleft is covered over by the lining (mucous membrane) of the roof of the mouth. This covering of mucosa makes the cleft difficult to see when looking in the mouth.

# Executive summary



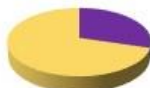
CRANE aims to audit, evaluate and report on the delivery of cleft services to children in England, Wales and Northern Ireland with the congenital abnormality of cleft lip and/or palate



18,985 children registered over the last eighteen years.



Approximately 1,055 new cases are registered in CRANE per year.



29.7% of children with a cleft palate received a delayed diagnosis (beyond 72 hrs after birth).

## 2017 births

All parents / carers of children born in 2017 were approached for consent. Of the families that had made their decision, 98.9% of these provided consent. This is extremely positive, as consent is essential for the collection of a full dataset and the linkage to other datasets.



## Key Findings

### 5-year olds: Outcomes



**Dental health**  
41%

of children with a cleft had at least one decayed, missing or filled tooth (>0 dmft), which is slightly higher than the rate in the general population (38.8%).



**Facial Growth**

No significant relationship was found between facial growth and speech among children with a complete unilateral cleft lip and palate.



**Speech**  
61%

of children with a cleft had speech scores that would suggest their speech was not significantly different from their non-cleft peers.



**Psychology**  
15%

of children with a cleft had high or very high 'Strengths and Difficulties' scores\*. This compares with 10% among their non-cleft peers.

### 7-year olds: Outpatient hospital appointments in England



Substantial differences exist between regions in outpatient service provision for children with a non-syndromic cleft. There are regional differences in:

- the number of annual appointments attended by patients, and
- the burden of care for relevant cleft-related specialties.

## Recommendations

### Clinical care

- Late diagnosis of cleft palate remains an important issue that must be addressed.
- Increased preventative dental support for children with a cleft seems essential to reduce dental decay, particularly among those at greatest risk of caries.

### Outcome measures and reporting to CRANE

- Units are encouraged to continue to build on the success of 100% of parents/carers approached for consent.
- Data submission to CRANE allow the expansion of analyses, linkage to other datasets, and reporting of cleft outcomes.

## Future directions

### Plan for 2019

- Continue work with our stakeholders to agree important cleft-related outcomes for older children and young adults that could be assessed by measures collected by the CRANE database. A multi-phase Delphi consensus process will be used.
- Extend our work on outpatient data to determine whether the number and type of appointments are associated with educational attainment.
- Expand our reporting of cleft-related outcomes as a result of linkage to other health and education datasets.

\*Scores in the 'high' and 'very high' ranges indicate a greater level of difficulties than low scores; classified as being in the 'close to average' range (indicating no concern).

# 1. Introduction

---

The Cleft Registry & Audit Network (CRANE) Database is a national register that was established in 2000 to collect information on children born with a cleft lip and/or palate in England, Wales and Northern Ireland<sup>2</sup>. The geographical representation of the cleft regions / units is detailed in [Appendix 3](#).

The Database collects birth, demographic and cleft diagnosis information. It also collects information about cleft-related treatment and outcomes. Hospital Episode Statistics (HES) is used to further examine treatment for cleft lip and/or palate in England.

The aims of the CRANE Database are:

1. to register birth, demographic and epidemiological data related to all children born in England, Wales and Northern Ireland with the congenital abnormality of cleft lip and/or palate;
2. to record the treatment of children and adults with a cleft lip and/or palate and the outcome of such treatment.

This Annual Report presents findings from data submitted to CRANE<sup>3</sup> for children with a cleft lip and/or palate born in England, Wales and Northern Ireland between the 1 January 2000 and 31 December 2017. We describe:

- the proportion of babies born in 2017, and registered in the CRANE Database, who were diagnosed at birth, referred within 24 hours of birth, and contacted within 24 hours of referral;
- cleft-related outcomes for children, registered in the CRANE Database, at five years of age (born 2004-2012);
- analyses of data from Hospital Episode Statistics (HES) data linked to the CRANE Database at the individual level for consented children born from 2004 to 2011. We describe the results exploring factors impacting on dental treatment and care among children with a cleft;
- analyses from Outpatient Hospital Episode Statistics (HES) data linked to the CRANE Database at the individual level for consented children who were in Year 2 of school, when most children turn seven years old, between 2006/07 and 2013/14. We describe the main specialties seen by children with a non-syndromic cleft and examine differences in appointments between the four main cleft types and the 13 cleft Units in England.

This Annual Report aims to provide feedback to all stakeholders involved in cleft care, highlighting areas of success and areas requiring improvement in future reporting and in clinical practice.

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<sup>2</sup> For further information on the background to the CRANE database please visit <https://www.crane-database.org.uk/>

<sup>3</sup> Registered in the CRANE Database by the 2 October 2017.

## 2. Methods

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This report contains information on patterns of care and outcomes derived from two sources of data. These sources are (1) the CRANE Database, and (2) CRANE Database data linked to Hospital Episode Statistics (HES) data.

### 2.1. CRANE

#### 2.1.1. Data source

CRANE is an online custom-built secure database that holds information on children born with a cleft lip and/or palate in England, Wales and Northern Ireland. CRANE collects data pertaining to a patient's birth, demographics, type of cleft, time of diagnosis, time of referral to a cleft team, and time of first contact between a patient and cleft team. CRANE also collects information about cleft-related treatment and outcomes. These data are reported to CRANE by the units that make up 10 Regional Cleft Centres / Managed Clinical Networks (as listed in [Appendix 3](#)). Each child born with a cleft in England, Wales and Northern Ireland should be referred to one of these units shortly after having their cleft diagnosed.

Since January 2012, CRANE has been able to act as a national register of cleft-affected births by collecting some basic information on all children born with a cleft and being treated by the specialist cleft units. Additional information, including cleft-related outcomes, is collected for children whose parents have consented to their child's data being submitted to the national database. Parental consent is usually obtained by units at some point between referral and the first primary repair. A coordinator within each unit submits data to CRANE on the children referred to them. Once a record has been created on CRANE for a particular child, it can later be updated with further information.

#### 2.1.2. Patients

All data entered into the CRANE Database by 11 July 2018 pertaining to children born between 1 January 2000 and 31 December 2017 is included in the descriptions and analyses described in this Annual report. Patients whose parents have not consented to their data being used by CRANE have been excluded from the sections and tables in this report on: (1) Five-year outcomes and (2) HES analyses (as the data presented in these sections and tables are not collected for non-consenting cases).

#### 2.1.3. Data validation and cleaning

Logical and systematic data cleaning was undertaken to identify any potential data errors. Continuous data variables (birth weight, five-year weight and five-year height) were assessed in

relation to valid ranges. Valid ranges for five-year body weight and five-year height have been defined according to growth charts published by the World Health Organisation (WHO)<sup>4</sup>.

#### 2.1.4. Analyses

Data have been analysed according to year of birth, unless otherwise stated. Five-year outcome data were restricted to children born between 2004 and 2012, depending on the outcome of interest. Children dying before five years of age were excluded from these analyses.

#### Cleft type

Cleft type was defined according to reported LAHSAL codes. The LAHSAL code is used to classify clefts, with each letter relating to one of the six parts of the mouth that can be affected by a cleft:

<b>L</b>	<b>A</b>	<b>H</b>	<b>S</b>	<b>A</b>	<b>L</b>
Right <u>L</u> ip	Right <u>A</u> lveolus	<u>H</u> ard palate	<u>S</u> oft palate	Left <u>A</u> lveolus	Left <u>L</u> ip

The code also indicates whether there is a complete cleft (upper case letter, e.g. H), an incomplete cleft (lower case letter, e.g. h), or no cleft (left blank). Where LAHSAL has not been reported (10.1% of children born in 2017), cleft type is based on the type reported by the region/ unit registering the child. Children with a unilateral cleft lip and palate (UCLP) were categorised according to whether the UCLP was complete or incomplete. A complete UCLP was defined as LAHS or HSAL codes, indicating a complete cleft affecting all three components of the mouth on either the right or left side.

#### Decayed, missing and filled teeth (dmft)

The dmft score describes the dental caries experience of an individual and is a measure of oral health. A dmft score reflects the total number of teeth that are decayed, missing or filled. Analyses on dmft data were restricted to consented children born between 2004 and 2011 (excluding children with a submucous cleft palate).

#### Five Year Old Index

Dental models of five-year old children with UCLP can be assessed using the Five Year Old Index to examine dental arch relationships. The index evaluates the effects of primary surgery on the facial growth of children with UCLP before any other interventions are performed, such as orthodontics or alveolar bone grafting, which may influence this growth further<sup>5</sup>. CRANE collected both internal and external Five Year Old Index scores for consented children born between 2004 and 2011 with a complete UCLP (LAHSAL codes LAHS or HSAL). Some units score the models of children treated in their unit (internal scores) before they are sent off to be scored externally (external scores) by a blinded process undertaken by calibrated examiners. For the purpose of this report we have

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<sup>4</sup> World Health Organization. The WHO Child Growth Standards 2011. Available from: <http://www.who.int/childgrowth/standards/en/>.

<sup>5</sup> Johnson N, Williams AC, Singer S, Southall P, Atack N and Sandy JR. Dentoalveolar relations in children born with a unilateral cleft lip and palate (UCLP) in Western Australia. The Cleft Palate-Craniofacial Journal, 2000. 37 (1): p. 12-16.



analysed externally validated scores where available; where these were unavailable, internal scores are included in the analyses.

### **Cleft Audit Protocol for Speech – Augmented (CAPS-A)**

CAPS-A ratings collected at five years of age among children born between 2009 and 2011 were reported to CRANE for consented children only. The parameters of speech assessed include resonance (hypernasality and hyponasality), nasal airflow (audible nasal emission and nasal turbulence) and twelve Cleft Speech Characteristics (CSCs) scores, including:

- anterior oral CSCs – for dentalisation/interdentalisation, lateralisation/lateral, and palatalisation / Palatal characteristics;
- posterior oral CSCs – for double articulation and backed to velar/uvular characteristics;
- non-oral CSCs – for pharyngeal articulation, glottal articulation, active nasal fricatives, and double articulation characteristics;
- passive CSCs – for weak and or nasalised consonants, nasal realisation of plosives, and gliding of fricatives.

### **Psychology**

Children are screened by psychologists at five years of age (and sometimes prior to that) using the Tiers of Involvement Measure (TIM) and the Strengths and Difficulties Questionnaire (SDQ). CRANE collected TIM and SDQ scores, as well as dates of psychological screening, for consented children born in 2011 with all cleft types.

The TIM is used to record the tier (level) of involvement when a Psychologist sees a patient/family in a Cleft Multi-Disciplinary Team (MDT) Clinic. The tiers are as follows:

0. Patient not seen by Psychologist.
1. Patient seen and psychosocial screen completed.
  - a. No psychological concerns requiring cleft psychological input.
  - b. Psychological support and/or needs met by other services e.g. Child and Adult Mental Health services (CAMHs).
2. Psychological input provided in clinic.
  - a. Preventative input only.
  - b. Input in response to a problem/concern raised by family/child.
  - c. Both preventative input and input in response to problem/concern raised by family/child.
3. Further action required by Psychologist but appointment not necessary (e.g. liaison with school, written information sent to family).



4. Psychologist appointment necessary (for the purposes of this report, TIM scores 4, 5 and 6 are included in this category<sup>6</sup>).

The SDQ is a brief behavioural screening questionnaire designed for use with 3-16 year olds. The SDQ asks about 25 attributes, some positive and others negative, which are divided between the following scales:

1. emotional symptoms (5 items)
2. conduct problems (5 items)
3. hyperactivity/inattention (5 items)
4. peer relationship problems (5 items)
5. prosocial behaviour (5 items)
6. scales 1 to 4 are added together to generate a 'Total difficulties' score (based on 20 items).

The CRANE Database collects the 'Total difficulties' score as well as the final scores for subscales 1 to 5, resulting from questionnaires completed by the parents of CRANE-registered children at five years of age<sup>7</sup>.

Exploration of the data collected using the six SDQ scores has been conducted according to their categorisation into the following four bands:

1. close to average
2. slightly raised
3. high
4. very high.

### Missing data

Missing data have been excluded from the denominators presented in all Tables and Appendices of this report. All units have some degree of missing data. The number of patients with missing data for five-year outcomes is high. A variety of reasons were reported by units. Reasons out of a unit's control include children not attending an appointment or moving away from the area.

## 2.2. Hospital Episode Statistics (HES)

HES is a national database containing records on all admissions to NHS hospitals in England. It includes data on private patients treated in NHS hospitals, patients who were resident outside of England and care delivered by treatment centres (including those in the independent sector) funded by the NHS. Data on admissions are available for every financial year from 1989/90 onwards. Since the 1997/98 financial year, a unique patient identifier has been available that enables records belonging to the same patient to be identified across years.

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<sup>6</sup> A score of 5 refers to a psychology appointment deemed as needed but resources do not allow for this to be offered in a timely way. A score of 6 refers to families who are already receiving psychology appointments when they are seen at age five years.

<sup>7</sup> Using the parent version for 4-16 year olds. Goodman R (1997) The Strengths and Difficulties Questionnaire: A Research Note. *Journal of Child Psychology and Psychiatry*, 38, 581-586. For more information visit [www.sdqinfo.com](http://www.sdqinfo.com)

The HES database holds diagnostic and procedure information on each patient, allowing us to identify those with a cleft lip and/or palate and those undergoing cleft-related treatment. In addition to being able to identify and confirm cleft type in the CRANE Dataset, HES is used by CRANE to identify any additional anomalies for the CRANE cohort (see [Appendix 4](#) for a list of the HES diagnosis and procedure codes used by CRANE). This allows the categorisation of children in CRANE as ‘non-syndromic’ or ‘syndromic’.

### **2.2.1. Outpatient hospital appointments at seven years of age in England**

A CRANE-National Pupil Database-HES linked dataset were used to identify a cleft cohort for analyses of hospital outpatient appointments. Children who were in National Curriculum Year 2 of schools in England between 1 September 2006 and 31 August 2014 were included in our analyses. Year 2 is the year in which most children turn seven years of age and undergo their Key Stage 1 teacher assessment. We have previously reported school absence for this cohort of children (see Annual Report 2016) and our aim for the present study was to report the volume and type of appointments attended by children with a non-syndromic cleft during the school year of interest.

There were 6,194 CRANE-registered children born from 2000 onwards who were previously matched to National Pupil Database (NPD) records (87% linkage rate). Of these, 4,928 had KS1 assessments and were in Year 2 between 2006/07 and 2013/14. As our primary interest was exploring cleft-related appointments, we excluded 1,401 children with additional anomalies (see Appendix 4 for list of diagnoses used to identify children as ‘syndromic’). In total, 3,527 non-syndromic children were included in our analyses of hospital appointments.

All outpatient hospital appointments attended by the study cohort were extracted from the HES Outpatient dataset, which contains individual records for all outpatient appointments occurring in England. Appointments occurring within the year (1 September to 31 August) each child had their KS1 assessment were included in our analyses. Duplicate appointments, identified as those occurring on the same date and under the same specialty, were excluded. Appointments occurring within the year of interest were summed for each child. Children were then categorised according to whether they had 0, 1, 2-5, 6-10, or >10 appointments in the 12-month period. Only attended appointments were included in analyses.

The HES outpatient dataset contains two specialty fields: Treating specialty and Main specialty. Both fields were used to determine the specialty of each appointment. We categorised appointment specialty into six groups: (1) Ear, nose and throat (ENT) and audiology, (2) Cleft-related surgery, (3) Dental, (4) Speech and language therapy (SLT), (5) Ophthalmology, and (6) Other, non-cleft. The first five appointment categories represented approximately 90% of all appointments attended by children with a non-syndromic cleft around the age of seven years. Around 2.8% of appointments had the treating specialty and the main specialty representing different categories, hence some totals are greater than 100%.

We performed analyses to explore differences in appointment volume and type between the four main cleft type groups and the 13 cleft administrative Units in England. Cleft type was based on the LAHSAL code in the CRANE database and cleft Unit was based on the Unit that the child is registered with on the CRANE database. It should be noted that the data presented according to cleft Unit may include outpatient appointments occurring at other hospitals in England.

Our analyses first examined the volume of appointments attended by children during the 12-month period of interest. We then explored the proportion of children attending appointments under each of the six specialty groups. This reflects the burden of hospital appointments faced by children with a cleft. Finally, we examined the proportion of all outpatient appointments made up by each of the six specialty groups. This reflects the burden of care on services and specialties.

## 3. CRANE

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In this chapter, we present findings on children with a cleft lip and/or palate, born between 1 January 2000 and 31 December 2017 in England, Wales and Northern Ireland. These data have been analysed to assess registration patterns, the timing of diagnosis, referral and contact with units around the time of birth, and cleft-related outcomes at five years of age.

### 3.1. Registrations and contact with cleft teams

Of the total 18,985 children born and registered in the CRANE Database over the last eighteen years<sup>8</sup>, 1,068 children have been registered in 2017. Among these 1,068 children:

- Cleft palate (CP) continues to be the most common of the four cleft types<sup>9</sup>, representing 40.1% of 2017 registrations.
- Bilateral cleft lip and palate (BCLP) is the least common type, representing 10.3% of 2017 registrations, while Cleft Lip (CL) represented 19.6% of registrations.
- Twenty percent of 2017 registrations were classified as unilateral cleft lip and palate (UCLP), of which 69.5% had complete UCLP (defined by either 'LAHS..' or '..HSAL' LAHSAL codes).
- Ten percent of registrations did not have their type of cleft specified (either by LAHSAL codes or by the units).

Visit the CRANE database website <https://www.crane-database.org.uk/> to review the Tables on registrations over the last 10 years, by cleft type and year of birth, according to region / unit.

With regards to families being referred to cleft teams in 2017:

- A total of 39.5% of registered children were missing data on referral time.
- Of the 646 children with a reported referral time, 82.5% were referred to a Cleft Unit within 24 hours of birth.
- The proportion of referrals within 24 hours of birth varied significantly according to cleft type ( $p < 0.001$ ), with CP patients having the lowest proportion of early referrals, which is consistent with later diagnosis times for these children.
- The proportion of referrals within 24 hours of birth also varied according to cleft /administrative unit, although not significantly.
- The patterns of referral according to time of diagnosis were consistent with patterns described in past years<sup>10</sup>.

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<sup>8</sup> 1 January 2000 and 31 December 2017.

<sup>9</sup> Cleft type is defined according to reported LAHSAL codes or, where LAHSAL has not been reported (for 10.1% of children registered in 2017), it is based on the cleft type reported by the region / unit registering the child.

<sup>10</sup> For past CRANE Database Annual Reports please visit <https://www.crane-database.org.uk>

With regards to families first being contacted by cleft teams in 2017:

- A total of 16.7% of registered children were missing the first contact time between units.
- Of the 890 children with a reported contact time, units established contact with 96.4% of parents within 24 hours of referral.
- The proportion of units establishing contact with parents within 24 hours of referral did not vary significantly according to cleft type. This is consistent with patterns described in past years<sup>11</sup>.
- The proportion of units establishing contact with parents within 24 hours of referral varied significantly according to the cleft /administrative unit ( $p < 0.001$ ) Despite this statistically significant variation between units, overall rates of contact within 24 hours remain high (as for previous reporting years).
- Overall, units contacted almost four in five (77.4%) parents of their patients within 24 hours of receiving the referral. This demonstrates the commitment of units to ensure a timely response to new referrals of babies born with a cleft, to help support these babies and their families in the important initial stages.

With regards to families being approached for consent to collect data into childhood (beyond registration and diagnosis):

- The parents/carers of all 1,068 children born in 2017 had a record of being approached for consent, which is extremely positive.
- Of the families approached for consent, the decision to provide consent (or decline consent) had been made by 64% of families<sup>12</sup>.
  - The proportion of families that had reached a decision to provide or decline consent to their children's data being collected by CRANE varied across the regions / units submitting data to CRANE (from 22% to 100%). Nevertheless, this remained consistent with proportions reported in past years (for detail on this please consult previous [CRANE Database Annual Reports](#)).
  - Of those families that had reached a decision to provide or decline consent, 98.7% of these agreed to their children's data being collected by CRANE (by providing consent). This is extremely positive.
- A marked improvement in the process for approaching parents for consent appears to have taken place in 2017 (and since reporting on this matter in previous Annual Reports). Although 35% of families approached in 2017<sup>12</sup> had yet to make their decision, regions' / units' approach to seeking consent in 2017 was extremely positive, as consent is essential for the collection of a full dataset and the linkage to other datasets.

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<sup>11</sup> For past CRANE Database Annual Reports please visit <https://www.crane-database.org.uk>

<sup>12</sup> Cleft/administrative units were awaiting decisions from 35% of families, and it had not been possible to consent 1% of families.

## 3.2. Characteristics of children born with a cleft lip and/or palate in 2017

All children born in 2017:

- Fifty-five percent of children born in 2017 were boys<sup>13</sup>. Boys were significantly more likely to have a CL, UCLP or BCLP than girls with a cleft (p<0.001)<sup>14</sup>.
- CP was significantly more prevalent among girls (54% vs. 46% in boys, p<0.001).
- Among the children born in 2017, five deaths were reported to CRANE (0.5% of registrations). Most of these occurred between one month and one year of age. It is not known from CRANE whether these children had additional anomalies or syndromes.

CRANE-consented children<sup>15</sup>:

- The mean gestation for those born in 2017 was 38.6 weeks (95% CI 38.4 to 38.8 weeks) and ranged from 27 to 42 weeks<sup>16</sup>.
- Forty (11.6%) babies were premature (born before 37 weeks' gestation), which is higher than the seven per cent national average in England and Wales<sup>17</sup>, although it should be noted that the gestation recorded in CRANE may not be representative of all babies born with a cleft lip and/or palate as 48.5% of consented children were missing this information.
- As for gestational age, a valid birth weight was reported for 346 (51.6%) consented babies born in 2017. The mean birth weight was 3.2kg (95% CI 3.1 to 3.2kg), which is consistent with the national average in England.

## 3.3. Timing of diagnosis

The majority of all babies born with a cleft in 2017 were diagnosed antenatally (46%) or at birth (41.9%). The proportion of children diagnosed antenatally varied significantly according to cleft type (p<0.001), with only 2.9% of children with CP diagnosed antenatally compared with rates of 69.2%, 86.1% and 89% for CL, BCLP and UCLP respectively. Please view '[Table 3. Diagnosis time](#)' on the CRANE database website for detail on cleft types and timing of diagnoses for all 2017 births.

### 3.3.1. Diagnosis times among CRANE children with a cleft palate alone, 2013-2017 births

The 2012 our Annual Report highlighted the issue of late diagnosis among children with CP, reporting that 1.1% were diagnosed during antenatal screening and 66.8% were diagnosed at birth,

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<sup>13</sup> Fourteen children did not have their sex reported to CRANE (1.3% of the total children registered)

<sup>14</sup> Males comprised 63% of CL cases, 64% of UCLP cases, and 63% of BCLP cases

<sup>15</sup> As these data are not collected for non-consenting cases.

<sup>16</sup> Gestational age was reported for 345 (51.5%) of the consented babies born in 2017. Therefore, further improvements in data completeness are required.

<sup>17</sup> Office for National Statistics. Gestation-specific infant mortality. Part of Gestation-specific infant mortality in England and Wales, 2013. Published 14 October 2015 (this is the latest release – checked November 2018). Available from: <http://www.ons.gov.uk/ons/rel/child-health/gestation-specific-infant-mortality-in-england-and-wales/2013/stb-gestation-specific-infant-mortality.html>.

leaving 32.1% who were diagnosed late according to the National Standard<sup>18</sup>. Because of this, we continue to investigate factors associated with a late CP diagnosis.

This year (as for previous years), we have examined diagnosis time among CP patients born over the last five years, between 1 January 2013 and 31 December 2017. No statistically significant differences were found between birth years ( $p=0.23$ ), indicating diagnosis times have not improved in recent years.

Table 1 shows the CP diagnosis times according to the region / unit. The proportion of CPs diagnosed at birth ranged from 61.3% (South Thames) to over 78.9% (West Midlands). This wide and significant variation ( $p<0.001$ ) suggests that practice varies considerably between maternity units, with some better than others at identifying a cleft of the palate during the newborn examination or due to problems with feeding.

Overall, 13% of children with a CP were not diagnosed until they were more than one week old, which is concerning given that the National Standard states that clefts should be diagnosed within 24 hours of birth to enable immediate referral to a specialist hospital. This helps to ensure the baby, and their family, receive appropriate care and support as soon as possible. Cleft services are advised to encourage their referring maternity units to identify all clefts as promptly as possible.

**Table 1.** Number (%) of CRANE-registered children born between 2013 and 2017 with a cleft palate, according to the timing of diagnosis and region / unit.

Regional Cleft Centre / MCN	Administrative Unit	Time of diagnosis in relation to birth <sup>a</sup>						All
		n (%)						
		Antenatal	At birth	≤1 week <sup>b</sup>	≤1 month	≤6 months	>6	
Northern & Yorkshire	Newcastle Leeds	1 (0.8)	78 (63.4)	15 (5.7)	9 (7.3)	15 (12.2)	5 (4.1)	123
North West & North Wales	Liverpool Manchester	5 (4.4)	80 (70.2)	17 (6.9)	4 (3.5)	6 (5.3)	2 (1.8)	114
Trent	Nottingham	1 (0.8)	102 (76.7)	18 (7.3)	4 (3)	4 (3)	4 (3)	133
West Midlands	Birmingham	0 (0)	123 (62.1)	46 (23.2)	8 (4)	14 (7.1)	7 (3.5)	198
East	Cambridge	2 (0.8)	202 (78.9)	32 (12.5)	9 (3.5)	9 (3.5)	2 (0.8)	256
North Thames	GOSH/Chelms	0 (0)	98 (73.1)	18 (13.4)	11 (8.2)	6 (4.5)	1 (0.7)	134
The Spire	Oxford/Salisbury	10 (3.7)	175 (64.6)	54 (19.9)	12 (4.4)	16 (5.9)	4 (1.5)	271
South Wales & South West	Swansea Bristol	2 (1.2)	122 (72.2)	26 (15.4)	10 (5.9)	8 (4.7)	1 (0.6)	169
South Thames	GSTT	0 (0)	58 (76.3)	9 (4.3)	7 (9.2)	1 (1.3)	1 (1.3)	76
N. Ireland	Belfast	8 (6.1)	86 (65.2)	18 (8.7)	12 (9.1)	7 (5.3)	1 (0.8)	132
All	All	3 (1.1)	174 (61.3)	71 (25)	13 (4.6)	15 (5.3)	8 (2.8)	284
		0 (0)	55 (66.3)	10 (12)	3 (3.6)	5 (6)	10 (12)	83
		33 (1.6)	1,452 (68.7)	353 (16.7)	110 (5.2)	113 (5.3)	52 (2.5)	2,113

**Note:** MCN - Managed Clinical Network.

<sup>a</sup> 133/2,246 (5.9%) missing diagnosis time and excluded from 'All' values.

<sup>b</sup> Recording of 'timing of diagnosis' within 72 hours commenced in May 2014 to align CRANE data collection with NIPE standards<sup>19</sup>. With only small numbers having been recorded using this timing, we report '≤72 hours' cases within the '≤1 week' timing (until recording of this timing is well established).

<sup>18</sup> Bannister P. Management of infants born with a cleft lip and palate. Part 1. Infant, 2008. 4(1): p. 5-8.

<sup>19</sup> UK National Screening Committee Newborn and Infant Physical Examination (NIPE) Standards and Competencies 1 document (2008) – setting out the standard for 95% newborn to be screened by 72 hours after birth (page 13 of the document found at <http://newbornphysical.screening.nhs.uk/getdata.php?id=10639>).

This year, for the second time, we conducted an exploration of the impact of different types of cleft palate based on the presentation (as recorded when reporting LAHSAL codes, as described in [Chapter 2](#)), on diagnosis times among children with cleft palate alone, born in the last five years between 1 January 2013 and 31 December 2017.

Table 2 shows that the completeness of the hard and soft palate impact on the timing of the CP diagnosis. Specifically:

- Children with CP including complete hard palates were significantly more likely to be identified at birth than those with incomplete hard palates ( $p < 0.001$ ). This delay is addressed within the next week, by which point 92.6% of CP cases have had this identified.
- CP cases with any type of hard palate were significantly more likely to be identified at birth (by almost 20%) than CP cases where there was no hard palate involvement ( $p < 0.001$ ). Where there was no hard palate involvement, 23.2% of CP cases remain undiagnosed until after a week had elapsed.
- CP cases with complete soft palates were significantly more likely to be identified at birth (by almost 30%) than incomplete soft palates ( $p < 0.001$ ). With an incomplete soft palate, 32.4% of these CP cases remain undiagnosed until after a week had elapsed.

**Table 2.** Number (%) of CRANE-registered children born between 2013 and 2017 with a cleft palate, according to complete / incomplete hard and soft palates.

Palate type	Status	Time of diagnosis in relation to birth						All*
		Antenatal	At birth	≤1 week	≤1 month	≤6 months	>6 months	
Hard	Incomplete (h)	12 (1.7)	500 (70.2)	131 (18.4)	31 (4.4)	30 (4.2)	8 (1.1)	712
	Complete (H)	16 (2.5)	528 (81.6)	72 (11.1)	18 (2.8)	12 (1.9)	1 (0.2)	647
All	All	28 (2.1)	1,028 (75.6)	203 (14.9)	49 (3.6)	42 (3.1)	9 (0.7)	1,359
Hard	No 'h' or 'H'	5 (0.7)	424 (56.2)	150 (19.9)	61 (8.1)	71 (9.4)	43 (5.7)	754
	Either 'h' or 'H' present	28 (2.1)	1,028 (75.6)	203 (14.9)	49 (3.6)	42 (3.1)	9 (0.7)	1,359
All	All	33 (1.6)	1,452 (68.7)	353 (16.7)	110 (5.2)	113 (5.3)	52 (2.5)	2,113
Soft Palate	Incomplete (s)	5 (1.6)	145 (46)	63 (20)	29 (9.2)	43 (13)	30 (9.5)	315
	Complete (S)	23 (1.3)	1,293 (73.2)	283 (16)	78 (4.4)	68 (3.8)	22 (1.2)	1,767
All	All	28 (1.3)	1,438 (69.1)	346 (16.6)	107 (5.1)	111 (5.3)	52 (2.5)	2,082

\*Totals for the sections of this table were based on where the hard and soft palate information had been reported as part of the LAHSAL code(s). Missing data have resulted in the variation in denominator.

### 3.4. Overview of outcomes among children born with a cleft lip and/or palate

Several outcomes are collected for CRANE-consented children when they are five years old. These include: height and weight, decayed missing and filled teeth (dmft), the Five Year Old Index, the Cleft Audit Protocol for Speech – Augmented (CAPS-A) ratings, and Psychology screening scores.



These are reported for only consented children born between 2004 and 2012 (excluding children with submucous cleft palates)<sup>20</sup>. Information and analyses of these data are presented in the next subsections.

### 3.4.1. Reporting of outcomes, for births from 2004

We describe the data completeness for outcomes, according to region/unit<sup>21</sup>, below:

- **Weight and Height at five years, for 2004-2012 births:** Despite improvements in reporting data over recent years, there is a high proportion of missing data for five-year old weight and height (for eligible children 62% and 62.5% missing respectively). There is also wide variation in reporting across regions, which ranged from 80% for both weight and height (Leeds) to less than 3% for both weight and height (Northern Ireland). This suggests that these data are not routinely collected in some regions.
- **Decayed, missing, filled teeth (dmft) index scores at five years, for 2004-2011 births:** The proportion of eligible children with reported dmft index scores varied across regions from 21.6% (Trent) to 79.6% (Newcastle).
- **Five Year Old Index scores, for 2004-2011 births:** The proportion of children with reported Five Year Old Index scores continues to increase year-on-year, which is encouraging. Nevertheless, there was wide variation in reporting of Five Year Old Index data across the regions/units from 26.2% (Swansea) to 88.3% (The Spires).
- **Cleft Audit Protocol for Speech – Augmented (CAPS-A) ratings at five years, for 2009-2011 births:** CRANE is encouraged by the fact that regions/units have shown increased rates in reported speech data year-on-year since the expanded 16 CAPS-A speech outcome scores were first requested in 2014. The proportion of eligible children with Speech outcome scores ranged from 47.8% (East) to 78.6% (Swansea).
- **Psychology screening scores at five years, for 2011 births:** The proportion of eligible children with reported Psychology screening scores varied across regions from 38.8% (Trent) to 100% (Northern and Yorkshire and South Thames regions). This is the first year that Psychology outcomes have been reported by the CRANE Database.

It is acknowledged that sometimes there are reasons outside the units' control as to why outcome data cannot be collected, and we encourage centres to report these. Nevertheless, it is positive to note that reporting has increased over recent years for some outcomes. It is hoped that this trend will continue over the next few years.

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<sup>20</sup> Submucous cleft palate patients excluded from all five year outcomes as all/most teams do not audit these patients.

<sup>21</sup> See Report number 1. 'Outcomes' behind the CRANE Database log-in for further detail- <https://www.crane-database.org.uk/>

### 3.5. Decayed missing and filled teeth (dmft) at five years, 2004-2011 births

The dmft describes the dental caries an individual has experienced and is a measure of oral health. A dmft score reflects the total number of teeth that are decayed, missing or filled. The risk of dental caries is thought to be higher among children with a cleft lip and/or palate compared with children without an oral cleft<sup>22</sup>. We collect dmft data on CRANE-registered consented children at five years of age.

Among children with a reported dmft outcome<sup>23</sup>, 40.8% of children with a cleft had at least one (>0) decayed, missing or filled tooth. The mean number of dmft at five years among children registered in CRANE was 2, with scores ranging from 0 to 20. Four hundred and seventy-five children (13.8%) had a dmft score greater than 5. This is equivalent to the figures reported for their non-cleft peers in Child Dental Health Survey 2013, England, Wales and Northern Ireland (ranging from 6% to 13%)<sup>24</sup>.

In the next two sections, we describe our exploration of the impact of cleft type and deprivation on dental treatment and care. HES data linked to the CRANE database at the individual level for consented children born between 1 January 2004 and 31 December 2011 were used to explore the impact of deprivation on dental treatment and care indices.

#### Dental Treatment and Care Indices

Table 3 shows the average treatment index and care index for children according to cleft type and deprivation quintile<sup>25</sup>. Both treatment and care indices are calculated from the dmft<sup>26</sup>, as raw dmft scores give a figure for dental disease experienced but do not distinguish between active and inactive disease at the time of exam (treatment index) or the proportion of children who have received care in the form of fillings (care index).

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<sup>22</sup> (1) Al-Dajani M. Comparison of dental caries prevalence in patients with cleft lip and/or palate and their sibling controls. *The Cleft Palate-Craniofacial Journal*, 2009. 46(5): p. 529-531. (2) Britton, KF and Welbury, RR, Dental caries prevalence in children with cleft lip/palate aged between 6 months and 6 years in the West of Scotland. *European Archives of Paediatric Dentistry*, 2010. 11 (5): p. 236-241.

<sup>23</sup> Submucous cleft palate patients excluded from all five year outcomes as all/most teams do not audit these patients.

<sup>24</sup> <https://digital.nhs.uk/data-and-information/publications/statistical/children-s-dental-health-survey/child-dental-health-survey-2013-england-wales-and-northern-ireland>

<sup>25</sup> Each quintile represents 20% of the population being described. The first quintile represents the lowest fifth of the data (1% to 20% - and in this case the most deprived); the second quintile represents the second fifth (21% to 40%) and so forth. The fifth quintile represents the highest fifth of the data (81% to 100% - the least deprived).

<sup>26</sup> Treatment Index calculated as = (Total number of missing teeth in primary dentition (m) + Total number of filled teeth in primary dentition (f)) / Total number of decayed, missing or filled teeth in primary dentition (dmft).

Care Index calculated as = Total number of filled teeth in primary dentition (f) / Total number of decayed, missing or filled teeth in primary dentition (dmft).

**Table 3.** CRANE-registered consented children born between 2004 and 2011 with a cleft lip and/or palate, according to cleft type and deprivation, and their average treatment index and care index at age five years.

		Treatment Index <sup>a</sup>		Care Index <sup>b</sup>	
		Average (%)	All (N)	Average (%)	All <sup>b</sup> (N)
<b>Cleft Type</b>	CL	(78.5)	920	(74.8)	923
	CP	(76.3)	1,725	(68.9)	1,727
	UCLP	(72.9)	1,141	(65.5)	1,146
	BCLP	(73.7)	472	(60)	472
	Not specified	(73.5)	33	(67.4)	33
<b>All</b>		<b>(75.6)</b>	<b>4,291</b>	<b>(68.3)</b>	<b>4,301</b>
<b>Deprivation</b>	Q1 – Most deprived	(62.8)	788	(51.2)	790
	Q2	(72.1)	728	(64.9)	731
	Q3	(77.6)	668	(69.2)	669
	Q4	(80)	658	(75.4)	659
	Q5 – Least deprived	(86)	709	(83)	709
<b>All</b>		<b>(75.3)</b>	<b>3,551</b>	<b>(68.2)</b>	<b>3,558</b>

<sup>a</sup> and <sup>b</sup> Exclusions from Treatment and Care Index (not mutually exclusive): Children who died before the age of five, children with submucous clefts, and cases without a dmft score of 0<sup>27</sup> or all relevant dmft data items (to allow calculation of treatment and care index scores).

Furthermore, Table 3 shows the average treatment index to be 75.6% and the average care index of 68.3% for children with a cleft assessed between 2009-2016 (considering these are 2004-2011 births). These figures are higher than the equivalent ones reported for their non-cleft peers in England (of 22.2% and 11.8% for treatment and care index respectively)<sup>28</sup>.

### Treatment index

The treatment index reflects whether the mouth is dentally fit at that moment in time. i.e. If dental disease has occurred, the treatment index indicates the extent to which it has been dealt with and the degree to which the child has been rendered free from active decay. When calculated, treatment indices range from 0 to 1 and are usually expressed as a percentage<sup>29</sup>. Treatment indices with a value of 1 (100%) indicate that there is no untreated disease, which is the desired outcome. Furthermore, average treatment indices of 100% can be indicators of having mechanisms in place to deal with any disease occurring, and thereby providing the child with a dentition where the disease is controlled and the child has a pain free mouth.

As shown in Table 3, for the 4,291 children with dmft scores of 0 or scores for all three ‘m’, ‘f’ and ‘dmft’ data items – to allow calculation of the treatment index – there was significant variation in *treatment index scores by cleft type* ( $p < 0.05$ ). Children with UCLP had the lowest average proportion

<sup>27</sup> If a dmft score for an individual is 0 then the treatment index and care index = 1 (100%) as there is no untreated dental disease.

<sup>28</sup> Data on non-cleft peers in Wales and Northern Ireland were not available at the time of producing this report. For England report visit <https://digital.nhs.uk/data-and-information/publications/statistical/children-s-dental-health-survey/child-dental-health-survey-2013-england-wales-and-northern-ireland>

<sup>29</sup> If a dmft score for an individual is 0 then the treatment index is 1 (100%) as there is no untreated dental disease.

of treated dental disease (73%; almost 3% less than the average for all cleft types), while children with CL had highest average proportion of treated dental disease (78.5%, almost 3% more than the average for all cleft types).

In addition, there was significant variation in *treatment index scores by deprivation* ( $p < 0.001$ ). Children in the most deprived quintile had the lowest average proportion of treated dental disease (62.8%; almost 13% less than the average for all cleft types), while those from the least deprived quintile had highest average proportion of treated dental disease (86%, at least 10% more than the average for all cleft types). For the whole population (including children with a cleft), children from the most deprived quintile have a higher caries rate and are least likely to be regularly accessing dental care.

### Care index

The care index reflects cases where children have experienced dental decay, which has been identified at the earliest possible stage (which is preferable), and have been provided with care in the least invasive form possible, in the form of fillings. When calculated, care indices also range from 0 to 1 and are usually expressed as a percentage<sup>30</sup>. Care indices with a value close to 1 (100%) indicate that there are high levels of care provided by fillings (not extraction or no treatment), which is the desired outcome. Conversely, in situations where levels of care are low (and decay could be addressed by filling but has not) the care index is close to 0%. Furthermore, average care indices of 100% can be indicators of having mechanisms in place to increase levels of care in relation to fillings.

As shown in Table 3, for the 4,301 children with dmft scores of 0 or scores for both 'f' and 'dmft' data items, to allow calculation of the care index, there was significant variation in *care index scores by cleft type* ( $p < 0.001$ ). Children with BCLP and unspecified cleft types had the lowest average care index (60% and 57.4% respectively, approximately 8-10% less than the average for all cleft types), which means decay that might be treated by fillings has remained untreated or decay was so severe that extraction was the treatment of choice. Children with BCLP and UCLP have a greater proportion of teeth with deficient enamel and dentine formation, and therefore the treatment option of choice is often extraction not restoration, due to the anatomy of the teeth. Meanwhile children with CL had the highest average proportion of children receiving care by fillings (74.8%, approximately 6% more than the average for all cleft types).

In addition, there was significant variation in *care index scores by deprivation* ( $p < 0.001$ ). Children in the most deprived quintile had the lowest average care index (51.2%, approximately 17% less than the average for all cleft types), which means decay that might be treated by fillings has remained untreated or decay was so severe extraction was the treatment of choice. Meanwhile, children in the least deprived quintile had the highest average proportion of children receiving care by fillings (83%, almost 15% more than the average for all cleft types). As for the treatment index, all children

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<sup>30</sup> If a dmft score for an individual is 0 then the care index is 1 (100%) as there is no dental disease.

(the whole population including cleft children) from the most deprived quintile have a higher caries rate and are least likely to be regularly accessing dental care.

It is worth considering that cleft type and deprivation differences in the levels of dental disease will not only be affected by the dental care received by children. Oral health will also be affected by ethnicity, cultural differences in attitudes to dental health and water fluoridation levels. A systematic review found that water fluoridation is associated with an increased proportion of children without caries and a reduction in the number of teeth affected by caries<sup>31</sup>. Fluoridation levels vary within and between regions throughout the UK. For example, parts of the West Midlands and parts of the North East receive fluoridated water, whereas other areas do not. Interestingly, data from 2005 revealed the West Midlands had one of the lowest proportions of five-year-olds with >0 dmft in the general population, while the North East had the highest proportion (50%)<sup>32</sup>. Accurate water fluoridation data will be useful for interpreting dmft regional differences and allowing for risk adjustment in the long term.

It is anticipated that we will be able to report on decayed missing and filled teeth (DMFT) at 10 years for 2007 and 2008 births in the CRANE 2019 Annual Report.

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<sup>31</sup> McDonagh M, Whiting P, Bradley M, Cooper J, Sutton A, Chestnutt I, et al. A systematic review of public water fluoridation. *BMJ*, 2000. 321: p. 855-859.

<sup>32</sup> Dental Health Services Research Unit from National Health Service - British Society for the Study of Community Dentistry data. Dental Caries Experience of 5-year-old Children in Great Britain 2005 / 2006. Available from: [http://www.app.dundee.ac.uk/tuith/search/tables/tab2005\\_6.htm](http://www.app.dundee.ac.uk/tuith/search/tables/tab2005_6.htm).

### 3.6. Five Year Old Index, 2004-2011 births

Dental models of five-year old children with a complete UCLP were assessed using the Five Year Old Index to examine dental arch relationships. The index evaluates the effects of primary surgery on the facial growth of children with UCLP before any other interventions, such as orthodontics or alveolar bone grafting, which may influence this growth further<sup>33</sup>. Dental arch relationships at five years are thought to predict treatment outcome in terms of facial growth on a population basis rather than at the individual child level<sup>34</sup>. The Five Year Old Index may, therefore, also be used to compare treatment outcomes between centres and surgeons. Patients scoring '1' and '2' on the index are considered to have the best possible outcomes, while those scoring '4' and '5' are thought to have poor outcomes in terms of facial growth, and they may benefit from further surgery to correct their facial disproportion once facial growth is complete.

The majority of Five Year Old Index scores provided by all regions/units were externally validated (in 786/881 (89.2%) of eligible cases), and where externally validated scores were unavailable, internal scores were included in the analysis. Overall, 42% of complete UCLP patients born between 2004 and 2011 had Five Year Old Index scores in the two groups considered to have the best possible dental arch relationships (scores '1' or '2') while 25.8% of children had scores '4' or '5', reflecting poor dental arch relationships. This represents an improvement, compared with the CSAG findings that 36% (of 223 cleft children) had poor dental arch relationships at five years old in 1998<sup>35</sup> (see [Appendix 5](#) for detail on children born between 2004 and 2011 with a complete unilateral cleft lip and palate, according to Five Year Old Index scores and region / unit).

The funnel plot<sup>36</sup> in Figure 1 further demonstrates the proportion of CRANE five-year olds with the poorest (4 and 5) Five Year Old Index outcome scores according to the number of children at each region / unit with index scores. It is centred on the national average of poor Five Year Old Index scores for CRANE five-year olds across all units of 25.8%<sup>37</sup>. It also shows that all regions' / units' rates of poor index scores fall within the expected range given the number of children (born between 2004-2011) with valid index scores at their unit. i.e. No unit has a 'poor index score rate' below the lower 99.8% control limit or above the upper 99.8% control limit (more information on funnel plots can be found in the Glossary at the front of this report).

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<sup>33</sup> Johnson N, Williams AC, Singer S, Southall P, Atack N and Sandy JR. Dentoalveolar relations in children born with a unilateral cleft lip and palate (UCLP) in Western Australia. *The Cleft Palate-Craniofacial Journal*, 2000. 37 (1): p. 12-16.

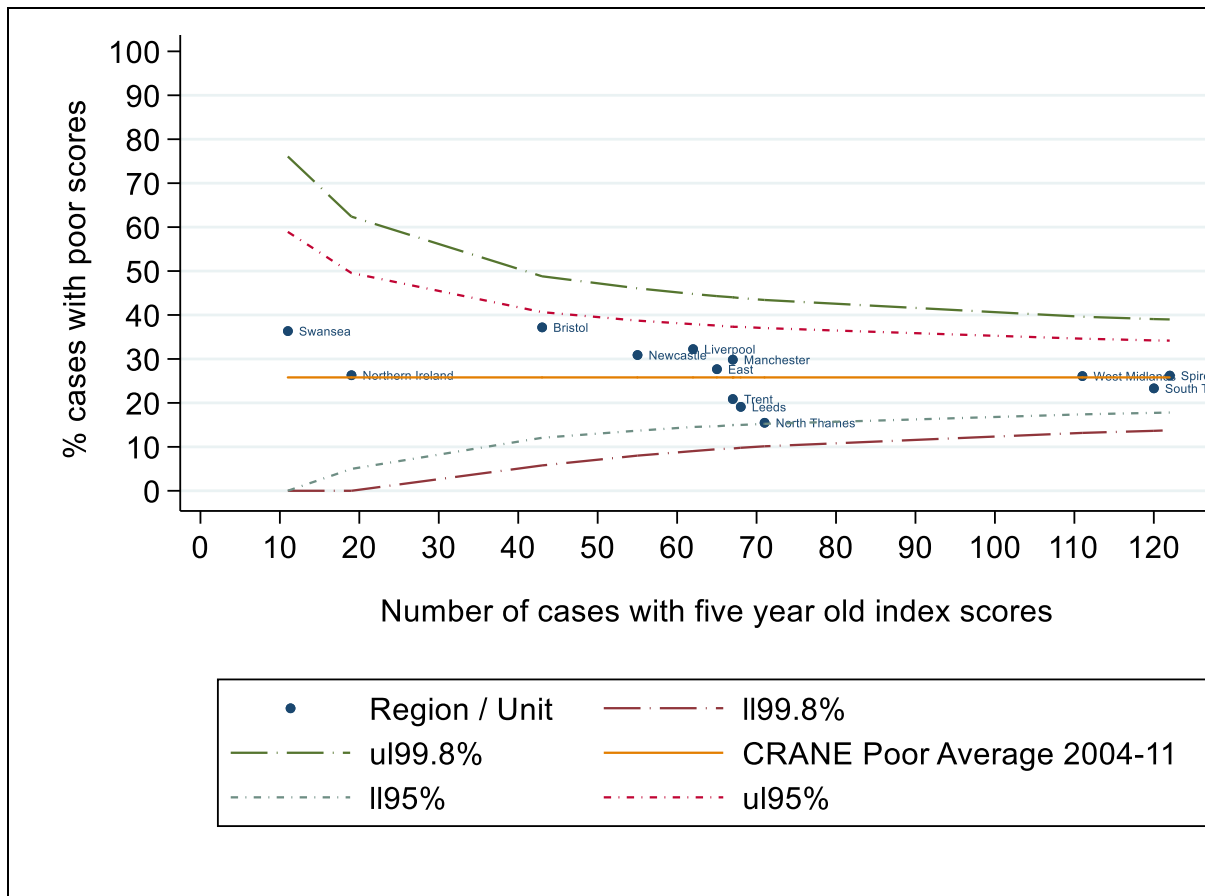
<sup>34</sup> Atack N, Hathorn IS, Semb G, Dowell T and Sandy JR. A new index for assessing surgical outcome in unilateral cleft lip and palate subjects aged five: reproducibility and validity. *The Cleft Palate-Craniofacial Journal*, 1997. 34 (3): p. 242-246.

<sup>35</sup> Clinical Standards Advisory Group, Clinical Standards Advisory Group. Report of a CSAG Committee on cleft lip and/or palate, 1998, The Stationery Office, London.

<sup>36</sup> This funnel plot is calculated using valid data as denominators (not considering missing data), subject to the same inclusions and exclusions as data in [Appendix 5](#). In addition, it is not adjusted (or risk adjusted) in any way.

<sup>37</sup> Versus the 36% national average identified by Clinical Standards Advisory Group (CSAG). Report of a CSAG Committee on cleft lip and/or palate, 1998, The Stationery Office, London.

**Figure 1.** Funnel plot of five-year olds (born between 2004 and 2011) with poor Five Year Old Index scores according to the number of children at each region / unit with index scores.



**Note:** Funnel plot centred on national average (for 2004-2010 births reported in CRANE) of poor Five Year Old Index scores across all units of 24.9%.

The fact that Five Year Old Index scores were submitted for only 70.4% of children, and the wide variation in the number of children within each region / unit (ranging from 11 to 122), means that the data presented in this section should be interpreted with caution, as it is possible that the overall findings from the limited data made available to CRANE may not be representative of the cleft population. Analyses of data from a greater number of children are necessary to examine true differences that may exist between regions / units.

### 3.7. Relationship between facial growth and speech at five years, 2007-2011 births

We sought to explore whether a relationship exists between facial growth and speech outcomes among children with a complete UCLP. Good outcomes for facial growth and speech have been defined as follows:

- Patients scoring ‘1’ and ‘2’ on the Five Year Old Index are considered to have the good facial growth, while those scoring ‘4’ and ‘5’ are thought to have poor facial growth (detailed in the previous section on Five Year Old Index scores).
- Normal speech is represented by ‘normal’ (green) scores across all 16 Cleft Audit Protocol for Speech – Augmented (CAPS-A) parameters (detailed further in the next section on CAPS-A ratings).

Table 4 shows that the proportion of children who have achieved normal speech is slightly higher among children classified as having good facial growth than those with poor facial growth; however, these differences were not statistically significant ( $p=0.48$ ).

**Table 4.** Number (%) of CRANE-registered<sup>a</sup> consented children born between 2007 and 2011<sup>b</sup>, with good or poor Five Year Old Index scores at five years of age, by those achieving/not achieving normal speech.

Five Year Old Index scores	Normal Speech				Total N
	Achieved		Not Achieved		
	N	(%)	N	(%)	
Good scores	90	(48.4)	96	(51.6)	186
Poor scores	53	(44.9)	65	(55.1)	118
<b>Total</b>	<b>143</b>	<b>(47.0)</b>	<b>161</b>	<b>(53.0)</b>	<b>304</b>

<sup>a</sup> Registered in CRANE by 11 July 2018.

<sup>b</sup> Excluding children who died before the age of five years, children with an incomplete UCLP, children with submucous cleft palates, syndromic children, children missing Five Year Old Index scores data, and children missing one or more of all 16 CAPS-A data items.

Overall, 29.6% (90/304) of consented children born between 2007 and 2011 had achieved scores indicating good facial growth and normal speech, while 21.4% (65/304) had scores indicating poor facial growth and not achieving normal speech.

We also explored the relationship between facial growth and children’s scores for the following six individual structurally-related CAPS-A speech parameters, whose poor scores are indicative of structural issues of the palate or poor surgery:

1. Resonance: Hypernasality
2. Nasal Airflow: Audible Nasal Emission
3. Nasal Airflow: Nasal Turbulence
4. Passive Cleft Speech Characteristics (CSCs): Weak and or nasalised consonants
5. Passive CSCs: Nasal realisation of plosives
6. Passive CSCs: Gliding of fricatives.



The proportion of children who had achieved good (green) scores for the above 6 CAPS-A speech parameters did not differ significantly between those with good or poor Five Year Index scores.

Our results, based on data provided for eligible children with complete UCLP, suggest that facial growth is not associated with speech scores. A small sample size means these findings should be interpreted with caution. Data should continue to be revisited as the sample increases in size. A larger sample will become available as the collection of the full 16 CAPS-A outcome scores (which started five years ago) expands for births after 2011. In addition, as the data completeness of Five Year Old Index and CAPS-A ratings continues to improve, so will the sample size available for analyses.

### **3.8. Cleft Audit Protocol for Speech – Augmented (CAPS-A) ratings at five years, 2009-2011 births**

The Cleft Audit Protocol for Speech – Augmented (CAPS-A) tool has been used to assess speech among children with a cleft affecting the palate (CP, UCLP and BCLP). The 16 CAPS-A speech parameters assessed include:

- Resonance (hypernasality and hyponasality) and nasal airflow (audible nasal emission and nasal turbulence). These are structurally related speech characteristics reflecting aspects such as the ability of the palate to close off the nasal airway during speech.
- 12 individual cleft speech characteristics (CSCs) grouped into four categories of CSCs (anterior oral, posterior oral, non-oral and passive) are also assessed. These reflect articulation patterns which can affect the clarity and intelligibility of a child's speech.

Table 5 shows the proportion of eligible cases that had reported speech outcomes, and the proportion with reasons for why they outcomes could not be collected by region / unit. Sixty-seven percent of consented children born between 2009 and 2011 had reported speech outcomes for all 16 CAPS-A parameters, and 23.3% had reported reasons why speech data were not collected (e.g. Patient transferred in or out of area, etc<sup>38</sup>).

Overall, rates of data completeness ranged from 66.7% of children being accounted for by the East regional centre to 98.2% of children being accounted for in Leeds.

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<sup>38</sup> Plus: Syndromic Diagnosis; Clinically contraindicated (other than syndromic) - this record type for this patient; Lack of staff / facilities / equipment; Patient DNA / cancelled / did not consent / cooperate; or Other reason.

**Table 5.** Number (%) of CRANE-registered<sup>a</sup> consented children born with a cleft palate in 2009-2011, with speech outcome data or reasons this outcome was not collected at five years of age, according to region / unit.

Regional centre / MCN	Administrative Unit	Eligible Consented cases	Speech <sup>b</sup>				
			Outcome Reported		Reason outcome not collected provided		Total cases acc. for (%)
			N	n (%)	n (%)		
Northern & Yorkshire	Newcastle	103	76 (73.8)	16 (15.5)	(89.3)		
	Leeds	114	87 (76.3)	25 (21.9)	(98.2)		
North West & North Wales	Liverpool	139	78 (56.1)	48 (34.5)	(90.6)		
	Manchester	164	113 (68.9)	40 (24.4)	(93.3)		
Trent	Nottingham	181	126 (69.6)	44 (24.3)	(93.9)		
West Midlands	Birmingham	211	156 (73.9)	39 (18.5)	(92.4)		
East	Cambridge	138	66 (47.8)	26 (18.8)	(66.7)		
North Thames	GOSH & Chelmsford	244	155 (63.5)	62 (25.4)	(88.9)		
The Spires	Oxford & Salisbury	188	127 (67.6)	45 (23.9)	(91.5)		
South Wales & South West	Swansea	98	77 (78.6)	16 (16.3)	(94.9)		
	Bristol	114	76 (66.7)	30 (26.3)	(93)		
South Thames	Guy's and St Thomas'	182	119 (65.4)	49 (26.9)	(92.3)		
Northern Ireland	Belfast	79	52 (65.8)	15 (19)	(84.8)		
<b>All</b>	<b>All</b>	<b>1,955</b>	<b>1,308 (66.9)</b>	<b>455 (23.3)</b>	<b>(90.2)</b>		

<sup>a</sup> Registered in CRANE by 11 July 2018. Note: MCN - Managed Clinical Network.

<sup>b</sup> Exclusions (not mutually exclusive): children who died before the age of five years, with submucous cleft palates, missing one or more of all 16 CAPS-A data items, born with either a CL or a non-specified cleft type, and syndromic children.

The ratings for each of the individual 16 CAPS-A speech parameters assessed are presented in [Appendix 6](#).

### Resonance and Nasal Airflow

In terms of resonance, 5.3% of children had moderate or severe hypernasality i.e. nasal sounding speech<sup>39</sup>. This is indicative of velopharyngeal dysfunction (VPD), which is when the palate is unable to close off the nasal airway during speech. In addition, results of the Cleft Speech Characteristics show that 3.6% of children had 'weak and or nasalised consonants' and 1.4% of children had 'nasal realisation of plosives' (passive articulation errors) affecting three or more consonants, which are likely to be the consequence of VPD and is consistent with the hypernasality scorings.

It should be noted that, in order to achieve good speech, 18.2% of the children with reported surgical data<sup>40</sup> have had secondary surgery for speech purposes before the age of five years.

Eighty-five percent of children with reported ratings for all four resonance and nasal airflow parameters had ratings indicating that no structural problems existed in relation to these parameters<sup>41</sup>.

<sup>39</sup> With a hypernasality score of '3' or '4' (red ratings).

<sup>40</sup> VP surgery/fistula repair data was reported for 99.4% of eligible children.

<sup>41</sup> All green ratings of '0' or '1'.

## Cleft Speech Characteristics (CSCs)

'Palatalisation / Palatal' anterior oral CSCs were the most commonly occurring CSC, affecting 23.4% of children (11.5% with ratings of one of two consonants affected (light green ratings) and 11.9% with three or more consonants affected (amber ratings) ratings). These CSCs can vary in severity and may affect speech acceptability more than speech intelligibility. The cleft speech characteristics which are more likely to affect speech intelligibility are the posterior, non-oral and passive CSCs. Therapy would often be indicated for these children, and/or further investigation of structure and possible surgery.

In addition, out of the 1,308 children with reported ratings for all 12 cleft speech characteristics, 66.5% had ratings indicating they did not exhibit any CSCs<sup>42</sup>.

## Nationally agreed Speech Outcome Standards

Further to reporting on the 16 CAPS-A speech parameters separately, we report on the proportion of five-year olds meeting each of the following three nationally agreed Speech Outcome Standards<sup>43</sup>:

1. The achievement of speech within the normal range (speech outcome standard #1): This standard is achieved in cases where patients have normal (green) ratings across all 16 CAPS-A speech parameters.
2. The absence of speech difficulties as a result of existing or previous structural anomalies (speech outcome standard #2a): This standard is achieved in cases where patients have no reported history of surgery for speech purposes and have normal (green) ratings across the following six CAPS-A speech parameters: Hypernasal resonance, both nasal airflow parameters (audible nasal emission and nasal turbulence), and all three Passive CSCs.
3. The absence of significant cleft-related articulation difficulties (speech outcome standard #3): This standard is achieved in cases where patients have normal (green) ratings across the following 10 CSCs: All three Anterior Oral CSCs, both Posterior Oral CSCs, all four Non Oral CSCs, and gliding of fricatives (a Passive CSC).

## Normal speech

Out of the 1,308 children (born 2009- 2011) with reported ratings for all 16 CAPS-A speech parameters, 61.2% of children across all units achieved the National Speech Outcome Standard 1. *They had normal (green) ratings across all 16 CAPS-A speech parameters.* This means that the National Speech Outcome Standard 1 benchmark of 55%<sup>44</sup> was achieved and exceeded by the CRANE cohort born in 2009-2011.

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<sup>42</sup> All green ratings of 'A' and in selected cases of 'B' – as per [Appendix 6](#).

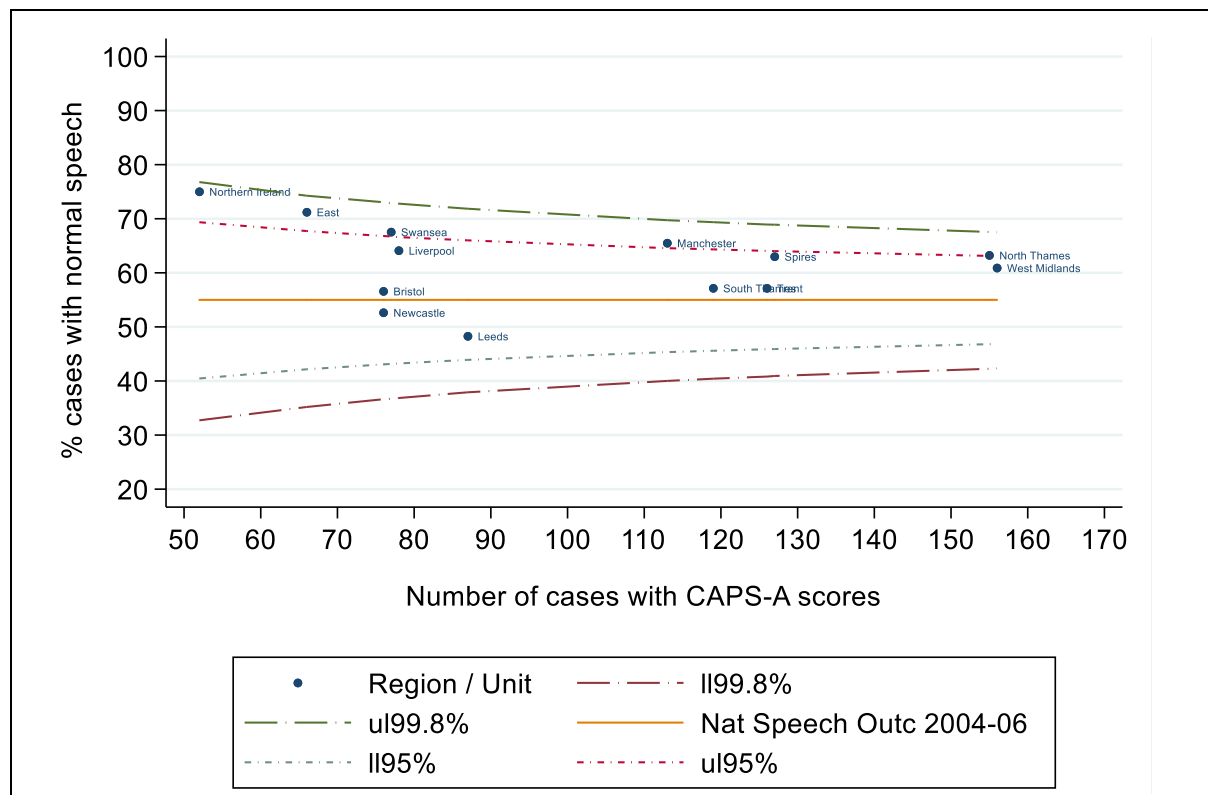
<sup>43</sup> Britton L, Albery L, Bowden M, Harding-Bell A, Phippen G, and Sell D(2014) A Cross-Sectional Cohort Study of Speech in Five-Year-Olds With Cleft Palate ± Lip to Support Development of National Audit Standards: Benchmarking Speech Standards in the United Kingdom. *The Cleft Palate-Craniofacial Journal*: July 2014, Vol. 51, No. 4, pp. 431-451.

<sup>44</sup> Based on the national outcome resulting from statistical analysis on 2004-06 Speech Outcome data – completed by the Lead Speech and Language Therapy Group, with statistical support from the Cleft Collective in Manchester, and presented in April 2014 to the Leads group.

Closer examination of the proportion of children achieving speech within the normal range at five years of age highlighted a statistically significant difference between the cleft types audited for speech ( $p < 0.001$ ). The proportion of children achieving *normal speech* was highest among those with CP and lowest among those with BCLP (74.4% vs 34.3%).

The funnel plot<sup>45</sup> in Figure 2 shows the proportion of children (born in 2009-2011) achieving *normal speech* according to the number of auditable children at each region / unit with ratings for all 16 CAPS-A speech parameters (more information on funnel plots can be found in the Glossary at the front of this report). It shows that rates of *normal speech*, for all regions / units, fell within the expected range given it is centred on the national speech outcome for 2004-06 births of 55%<sup>46</sup> and the number of children with valid speech ratings at each unit. I.e. no unit has *normal speech* rates below the lower 99.8% control limit, which is positive.

**Figure 2.** Funnel plot of five-year olds (born 2009-2011) with ratings suggesting speech within the normal range, according to the number of children at each region / unit with CAPS-A ratings.



**Note:** Funnel plot centred on the national speech outcome for 2004-06 births<sup>47</sup> of 55%.

<sup>45</sup> This funnel plot is calculated using valid data as denominators (not considering missing data), subject to the same inclusions and exclusions as data in Table 8. In addition, it is not adjusted (or risk adjusted) in any way.

<sup>46</sup> This is the proportion of children, nationally, meeting the standard across the 3 years. I.e. the cumulative total/proportion of children meeting the standard (not by year, to account for small volumes of cases across centres).

<sup>47</sup> Resulting from statistical analysis on 2004-06 Speech Outcome data completed by the Lead Speech and Language Therapy Group, with statistical support from the Cleft Collective in Manchester, and presented in April 2014 to the Leads group.

Nevertheless, this graphical representation of the data showing high levels of *normal speech* achieved in Northern Ireland (75%) and lower levels of *normal speech* achieved in Leeds (48.3%) – should be interpreted with caution as there is wide variation in rates of missing data between regions/units, and speech outcomes at five years of age are indicative of historical rather than current service provision. See [Appendix 7](#) for the table of data used to create this funnel plot.

### **Children with no evidence or history of a structurally related speech problem**

Out of the 1,308 children (born 2009-2011) with reported ratings for all 16 CAPS-A speech parameters, 72.3% of children across all units achieved the National Speech Outcome Standard 2a. *They had no reported history of surgery for speech purposes and normal (green) ratings across the following six CAPS-A speech parameters: Hypernasal resonance, both nasal airflow parameters (audible nasal emission and nasal turbulence), and all three Passive CSCs.* This means the National Speech Outcome Standard 2a benchmark of 67%<sup>48</sup> was achieved and exceeded by the CRANE cohort born 2009-2011.

Figure 3 shows the proportion of five-year olds with speech ratings that suggest they do not have structurally related speech difficulties<sup>49</sup>, according to the number of children at each region / unit with CAPS-A ratings. It is centred on the national speech outcome for 2004-06 births of 67%<sup>50</sup>, and shows that, with the exception of one region / unit, rates of *no structurally related speech difficulties* fall within the expected range given the number of children with CAPS-A ratings at their region / unit. The West Midlands have significantly high rates of children without structurally related speech difficulties (with rates above the upper 99.8% control limit), which is unlikely to be the result of chance and may be worth investigating.

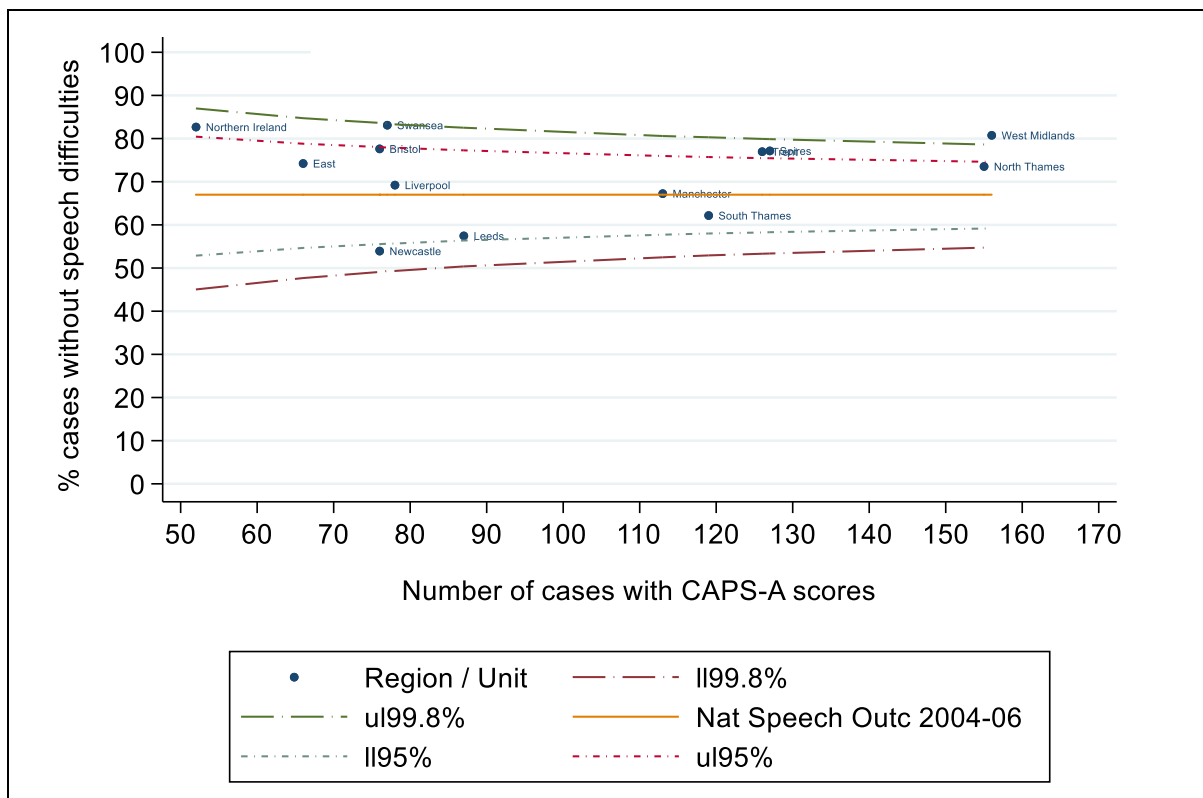
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<sup>48</sup> Based on the national outcome resulting from statistical analysis on 2004-06 Speech Outcome data – completed by the Lead Speech and Language Therapy Group, with statistical support from the Cleft Collective in Manchester, and presented in April 2014 to the Leads group.

<sup>49</sup> As a result of existing or previous structural anomalies – specifically there is no evidence of a structurally related problem and they have not had VP surgery or fistula repair for speech.

<sup>50</sup> Resulting from statistical analysis on 2004-06 Speech Outcome data completed by the Lead Speech and Language Therapy Group, with statistical support from the Cleft Collective in Manchester, and presented in April 2014 to the Leads group.

**Figure 3.** Funnel plot of five-year olds (born 2009-2011) with ratings suggesting no structurally related speech difficulties, according to the number of children at each region / unit with CAPS-A ratings.



**Note:** Funnel plot centred on the national speech outcome for 2004-06 births<sup>51</sup> of 67%.

See [Appendix 7](#) for the table of data used to create this funnel plot.

### Children without cleft-related articulation difficulties

Out of the 1,308 children (born 2009-2011) with reported ratings for all 16 CAPS-A speech parameters, 68.2% of children across all units achieved the National Speech Outcome Standard 3. They had normal (green) ratings across the following 10 CSCs: All three Anterior Oral CSCs, both Posterior Oral CSCs, all four Non Oral CSCs, and gliding of fricatives (a Passive CSC). This means the national Speech Outcome Standard 3 benchmark of 65%<sup>52</sup> was achieved and exceeded by the CRANE cohort born 2009-2011

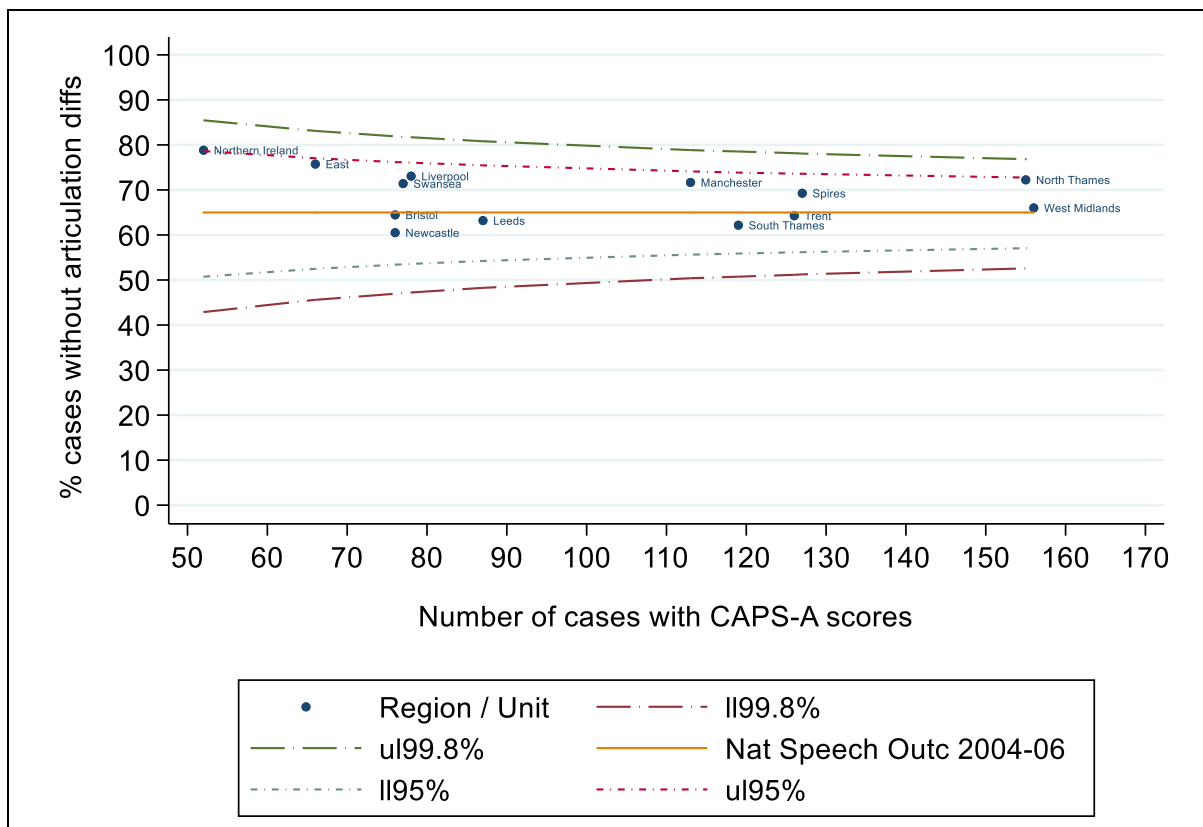
Figure 4 shows the proportion of five-year olds with speech ratings that suggest they do not have cleft-related articulation difficulties<sup>53</sup>, according to the number of children at each region / unit with CAPS-A ratings. It is centred on the national speech outcome for 2004-06 births of 65%, and shows that all regions' / units' rates of 'no articulation difficulties' fall within the expected range given the number of children with valid CAPS-A ratings at their region / unit.

<sup>51</sup> Resulting from statistical analysis on 2004-06 Speech Outcome data completed by the Lead Speech and Language Therapy Group, with statistical support from the Cleft Collective in Manchester, and presented in April 2014 to the Leads group.

<sup>52</sup> Based on the national outcome resulting from statistical analysis on 2004-06 Speech Outcome data – completed by the Lead Speech and Language Therapy Group, with statistical support from the Cleft Collective in Manchester, and presented in April 2014 to the Leads group.

<sup>53</sup> No cleft type speech characteristics requiring SLT and/or surgery.

**Figure 4.** Funnel plot of five-year olds (born 2009-2011) with ratings suggesting no cleft-related articulation difficulties, according to the number of children at each region / unit with CAPS-A ratings.



**Note:** Funnel plot centred on the national speech outcome for 2004-06 births<sup>54</sup> of 65%.

See [Appendix 7](#) for the table of data used to create this funnel plot.

Despite the considerations around missing data described above, presenting the data in Figures 2, 3 and 4 as funnel plots centred on national outcomes<sup>55</sup> is the most conservative method (at this time<sup>56</sup>) of checking whether or not any units deviate significantly from the expected standards.

### Cleft Audit Protocol for Speech – Augmented (CAPS-A) ratings, future work

We have met with the Lead SLT group to explore potential projects we could take forward in collaboration. These include exploring:

- linking speech outcomes with Education data from NPD (Key Stage 1 / Early Years Foundation Stage);
- investigating the effect of centralisation of care on speech outcomes since CSAG;

<sup>54</sup> Resulting from statistical analysis on 2004-06 Speech Outcome data completed by the Lead Speech and Language Therapy Group, with statistical support from the Cleft Collective in Manchester, and presented in April 2014 to the Leads group.

<sup>55</sup> Resulting from statistical analysis on 2004-06 Speech Outcome data completed by the Lead Speech and Language Therapy Group, with statistical support from the Cleft Collective in Manchester, and presented in April 2014 to the Leads group.

<sup>56</sup> No consensus has been reached on the factors that should be incorporated into an adjustment (or risk adjustment) of this data.

- undertaking a comparison of speech and educational outcomes for children born with Pierre Robin Sequence;
- the effect of late repair on speech outcomes;
- the effect of secondary speech surgery rates (and/or late repair from HES data) on speech outcomes;
- investigating the speech outcomes for children with a syndrome and how these differ from non-syndromic cleft cohort.

We aim to explore these further with the group as we acquire the data from the proposed linkage as described in [Chapter 5. Development of CRANE Database and future directions](#).



### 3.9. Psychology screening scores at five years, 2011 births

This is the first year that Psychology outcomes have been reported in the CRANE Database Annual Report. The assessed parameters of psychology include:

- a. date of first face-to-face psychosocial screening,
- b. date of psychosocial screening at age five,
- c. the Tiers of Involvement Measure (TIM),
- d. the Strengths and Difficulties Questionnaire (SDQ), made up of five subscales which contribute to a total score, and
- e. where the above were not collected, a reason as to why the outcome was not collected (as for all other CRANE outcomes).

*The Tiers of Involvement Measure (TIM)* is used to record the tier (level) of involvement when a psychologist sees a patient/family in a Cleft Multi-Disciplinary Meeting (MDT) Clinic. The tiers are as follows:

0. Patient not seen by Psychologist.
1. Patient seen and psychosocial screen completed.
  - a. No psychological concerns requiring cleft psychological input.
  - b. Psychological support and/or needs met by other services e.g. Child and Adult Mental Health services (CAMHs).
2. Psychological input provided in clinic.
  - a. Preventative input only.
  - b. Input in response to a problem/concern raised by family/child.
  - c. Both preventative input and input in response to problem/concern raised by family/child.
3. Further action required by Psychologist but appointment not necessary (e.g. liaison with school, written information sent to family).
4. Psychologist appointment necessary (for the purposes of this report, TIM scores 4, 5 and 6 are included in this category<sup>57</sup>).

*The Strengths and Difficulties Questionnaire (SDQ)* is a brief behavioural screening questionnaire designed for use with 3-16 year olds. The SDQ asks about 25 attributes, some positive and others negative which are divided between the following scales:

1. emotional symptoms (5 items)
2. conduct problems (5 items)
3. hyperactivity/inattention (5 items)
4. peer relationship problems (5 items)
5. prosocial behaviour (5 items)

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<sup>57</sup> A score of 5 refers to a psychology appointment deemed as needed but resources do not allow for this to be offered in a timely way. A score of 6 refers to families who are already receiving psychology appointments when they are seen at age five years.

6. scales 1 to 4 are added together to generate a 'Total difficulties' score (based on 20 items).

The CRANE Database collects the 'Total difficulties' score as well as the final scores for subscales 1 to 5, resulting from questionnaires completed by the parents of CRANE-registered children at five years of age<sup>58</sup>.

Exploration of the data collected using the six SDQ scores has been conducted according to their categorisation into the following four bands:

1. close to average
2. slightly raised
3. high
4. very high.

Low scores, indicating no concern, are classified as being in the 'close to average' range. Scores in the 'high' and 'very high' ranges indicate a greater level of difficulties.

Psychology data were recorded in CRANE for 745 (83%)<sup>59</sup> of 898 eligible children born in 2011, whose parents have given consent for their outcomes to be collected and recorded on the database<sup>60</sup>. Data completeness for these cases is shown in [Appendix 8](#), by region/unit.

The figures presented throughout this section of the CRANE report are calculated using valid data as denominators (see [Appendix 8](#) for detail of missing data).

### 3.9.1. Date of first face-to-face psychosocial screening

The date of the first face-to-face screening was recorded in CRANE for 566 children (63% of the total 898 eligible children)<sup>61</sup>.

- The average age of children at the time of their 'first face-to-face psychosocial screen' was 1 year and 8 months, with half of these children having their first screening before they were 6-months-old<sup>62</sup>.
- Sixty-three percent of children were seen before their first birthday.
- Seventy-nine percent of children had their first face-to-face psychosocial screen before the age of five, and 99% before the age of six<sup>63</sup>.

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<sup>58</sup> Using the parent version for 4-16 year olds. Goodman R (1997) The Strengths and Difficulties Questionnaire: A Research Note. *Journal of Child Psychology and Psychiatry*, 38, 581-586. For more information visit [www.sdqinfo.com](http://www.sdqinfo.com)

<sup>59</sup> This means that at least 1 out of the 9 psychology items collected by CRANE has been recorded, or they had a recorded exclusion reasons – as per shown in [Appendix 8](#).

<sup>60</sup> Registered in the CRANE Database by the 11 July 2018, and eligible for Psychology outcomes data to be added. Eligibility exclusions (not mutually exclusive): (Consent), children who died before the age of 5 years, with submucous cleft palates, and syndromic children.

<sup>61</sup> 3 cases had a recorded date of 'first face-to-face psychosocial screen' prior to their date of birth. These are excluded from reporting in section 2.

<sup>62</sup> The age of the oldest child children at the time of their 'first face-to-face psychosocial screen' was 6 years and 4 months.

<sup>63</sup> 20% of children had their first face-to-face psychosocial screen at the age of 5.

Although clinical psychologists have a target to see all children and families born with a cleft for a face-to-face psychosocial screen before the age of six years, families would ideally be seen earlier than this, where team resources and structures allow. *This data demonstrates that, where data have been supplied, families were almost all seen before the target age of six years and that the majority (63%) were seen for a psychosocial screen within the first year of the child’s life.*

### 3.9.2. Date of psychosocial screening at age five

The date of the psychosocial screening at age five was recorded in CRANE for 510 children (57% of the total 898 eligible children)<sup>64</sup>, with 98% of these children and families having their ‘psychosocial screen at age five’ before the age of six, thereby meeting the target for the collection of outcome audit data at age five.

### 3.9.3. The Tiers of Involvement Measure (TIM)

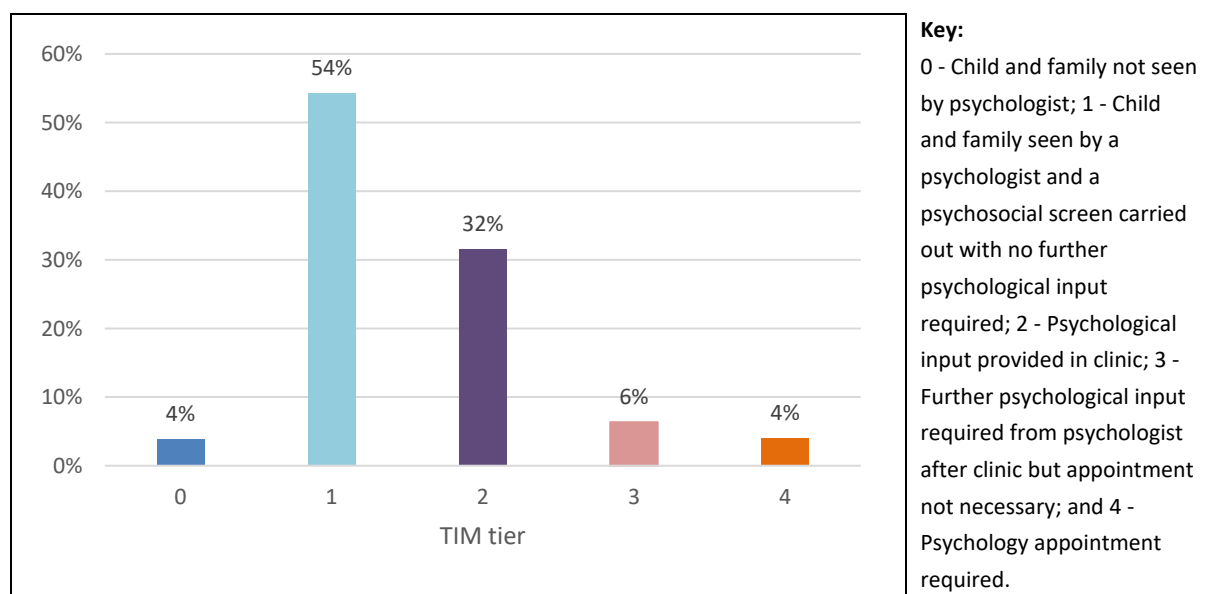
#### Proportion of children by TIM level

The TIM was recorded in CRANE for 473 children (53% of eligible children). Among these children, our analyses revealed that:

- Ninety-six percent were seen by a psychologist and a psychosocial screen was completed (tiers 1 to 4).
- Forty-two percent received psychological input, either in clinic or after clinic (tiers 2, 3 and 4).

These data are shown in Figure 5 below.

**Figure 5.** Proportion of CRANE-registered consented children<sup>65</sup> born with a cleft lip or palate (2011), according to the Tiers of Involvement Measure (TIM) levels of psychological involvement / input received.



<sup>64</sup> 1 case had a recorded a date of ‘psychosocial screening at age 5’ prior to their date of birth. These are excluded from reporting in section 3.

<sup>65</sup> Eligibility exclusions (not mutually exclusive): (Consent), children who died before the age of 5 years, with submucous cleft palates, and syndromic children.

- Of those seen by a psychologist and had a psychosocial screen completed (tiers 1 to 4, n=455), 53% had no psychological concerns identified (tier 1a, n=241).
- Of those seen by a psychologist and had a psychosocial screen completed but not receiving psychological input (all tier 1, n=257), the majority (94%) had no psychological concerns identified (tier 1a, n=241). A small group were having their psychological concerns or needs met by another service (tier 1b, n=16).
- Of those receiving psychological input in clinic (tier 2, n=149):
  - Seventy-seven percent received preventative input (tiers 2a and 2c, n=68 and n=47). This is most likely to be in relation to helping children prepare for dealing with comments and questions from others about cleft-related factors but will also include other psychosocial issues.
  - Fifty-four percent received input in response to a concern raised by the family (tiers 2b and 2c, n=38 and n=47). Examples of concerns include behaviour or developmental concerns.
  - Thirty-two percent received both preventative input and input in response to a concern (tier 2c, n=47).
- Ten percent of all children with recorded TIM scores received further input after clinic (tiers 3 and 4, n=30 and n=19), with a minority being offered a separate psychological appointment (tier 4).

### TIM levels by cleft type

As shown in Table 6, generally TIM scores were spread evenly across cleft types, in similar proportions as would be expected from general cleft type prevalence data, with a few exceptions and notable points

**Table 6.** Number (%) of CRANE-registered consented children<sup>66</sup> born with a cleft lip or palate (2011), according to Tiers of Involvement Measure (TIM) levels and cleft type.

TIM level	n (%)					All
	CL	CP	UCLP	BCLP		
0	9 (50)	5 (27.8)	3 (16.7)	1 (5.5)	<b>18 (100)</b>	
1a	50 (21)	103 (43.3)	62 (26.1)	23 (9.6)	<b>238 (100)</b>	
1b	1 (6.2)	9 (56.3)	5 (31.3)	1 (6.2)	<b>16 (100)</b>	
2a	32 (47.1)	12 (17.6)	16 (23.5)	8 (11.8)	<b>68 (100)</b>	
2b	4 (11.8)	15 (44.1)	12 (35.3)	3 (8.8)	<b>34 (100)</b>	
2c	12 (25.5)	15 (31.9)	13 (27.7)	7 (14.9)	<b>47 (100)</b>	
3	4 (14.9)	12 (44.4)	6 (22.2)	5 (18.5)	<b>27 (100)</b>	
4	5 (26.3)	5 (26.3)	7 (36.8)	2 (10.6)	<b>19 (100)</b>	
<b>All</b>	<b>117 (25.1)</b>	<b>176 (37.7)</b>	<b>124 (26.6)</b>	<b>50 (10.6)</b>	<b>467 (100)</b>	

**Key:** 0 - Child and family not seen by psychologist; 1 - Child and family seen by a psychologist and a psychosocial screen carried out with no further psychological input required (1a. No input required; 1b. Needs met by another service); 2 - Psychological input provided in clinic (1a. preventative input only; 2b. In response to problem or concern; 2c. As per both 2a and 2b); 3 - Further psychological input required from psychologist after clinic but appointment not necessary; and 4 - Psychology appointment required.

<sup>66</sup> Eligibility exclusions (not mutually exclusive): (Consent), children who died before the age of 5 years, with submucous cleft palates, and syndromic children.

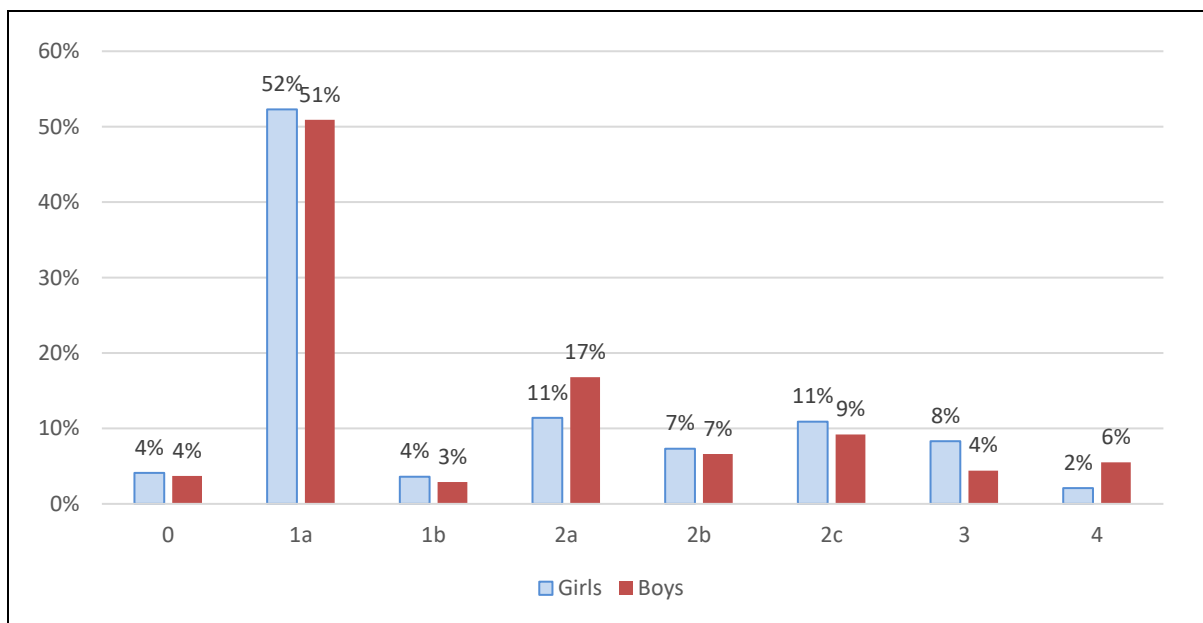
- Of those patients not seen (tier 0), 50% had a cleft lip.
- Of those receiving psychological input in clinic (tier 2, n=149), patients with a cleft lip only were more likely to have received preventative psychological input only (2a only).
- The families who were offered a psychological appointment (tier 4), were spread across all cleft types. The numbers of families involved is fairly small (n=19) but this suggests that, for this cohort, cleft type does not predict those families who require or would benefit from an additional psychology appointment.

### TIM levels by Sex

As shown in Figure 6, showing proportions of girls and boys by TIM level, for most TIM scores there was an equal split of girls and boys, with three exceptions:

- A higher percentage of boys (17%) than girls (11%) received input in clinic that was preventative only (tier 2a, n=68 in total).
- A higher percentage of girls (8%) than boys (4%) received further psychological input after clinic but did not require an appointment (numbers are small in the tier 3 group, n=28 in total).
- A higher percentage of boys (6%) than girls (2%) received an additional psychology appointment (numbers are small in the tier 4 group, n=19 in total).

**Figure 6.** Proportion of CRANE-registered consented girls and boys<sup>67</sup> born with a cleft lip or palate (2011), according to the Tiers of Involvement Measure (TIM) levels of psychological involvement / input received.



**Key:** 0 - Child and family not seen by psychologist; 1 - Child and family seen by a psychologist and a psychosocial screen carried out with no further psychological input required (1a. No input required; 1b. Needs met by another service); 2 - Psychological input provided in clinic (1a. preventative input only; 2b. In response to problem or concern; 2c. As per both 2a and 2b); 3 - Further psychological input required from psychologist after clinic but appointment not necessary; and 4 - Psychology appointment required.

<sup>67</sup> Eligibility exclusions (not mutually exclusive): (Consent), children who died before the age of 5 years, with submucous cleft palates, and syndromic children.

## TIM levels by Strengths and Difficulties Questionnaire (SDQ) 'Total difficulties' scale bands

We explored the relationship between the TIM levels and SDQ 'Total difficulties' scale bands.

Table 7 shows the proportion of children within each TIM level according to collapsed SDQ Total difficulties scale bands. Children scoring in the 'high' and 'very high' range on the SDQ are grouped together (n=59), and children scoring in the 'close to average' or 'slightly raised' ranges are grouped together (n=350). Please see [Appendix 8](#) for the detailed breakdown by the four SDQ Total difficulties scale bands.

**Table 7.** Number (%) of CRANE-registered consented children<sup>68</sup> born with a cleft lip or palate (2011), according to grouped Tiers of Involvement Measure (TIM) levels and SDQ Total difficulties scale bands.

SDQ	TIM								All
	0	1a	1b	2a	2b	2c	3	4.	
Cl to aver./ SI raised	13 (3.7)	198 (56.6)	7 (2)	56 (16)	27 (7.7)	25 (7.1)	15 (4.3)	9 (2.6)	<b>350 (100)</b>
High / Very high	2 (3.4)	14 (23.7)	6 (10.2)	5 (8.5)	6 (10.2)	11 (18.6)	6 (10.2)	9 (15.3)	<b>59 (100)</b>
<b>All</b>	<b>15 (3.7)</b>	<b>212 (51.8)</b>	<b>13 (3.2)</b>	<b>61 (14.9)</b>	<b>33 (8.1)</b>	<b>36 (8.8)</b>	<b>21 (5.1)</b>	<b>18 (4.4)</b>	<b>409 (100)</b>

**Key:** 0 - Child and family not seen by psychologist; 1 - Child and family seen by a psychologist and a psychosocial screen carried out with no further psychological input required (1a. No input required; 1b. Needs met by another service); 2 - Psychological input provided in clinic (1a. preventative input only; 2b. In response to problem or concern; 2c. As per both 2a and 2b); 3 - Further psychological input required from psychologist after clinic but appointment not necessary; and 4 - Psychology appointment required

- Of the small number of families who were recorded as not having been seen by a psychologist (tier 0) at age five, most (87%, 13 of 15) of the children had a 'close to average' SDQ Total score.
- Of those children scoring in the 'high' and 'very high' range on the SDQ (n=59):
  - Forty-nine percent were seen by a psychologist and either had their psychological needs met by another service (tier 1b, 10%), received psychological input in response to a concern in clinic (tier 2b and 2c, 29%), or after clinic (tier 3, 10%).
  - Fifteen percent were offered a separate psychology appointment (tier 4).
  - Considering the remaining 36%: 24% were seen by a psychologist and no psychological concerns were identified (tier 1a), 8% were provided with preventative psychological input in clinic (tier 2a), and 3% were not seen by a psychologist (tier 0).
  - *This demonstrates that for the majority of children with an elevated SDQ score (64%), the cleft team psychologist identified psychological concerns and provided psychological input to the family, if required.*
- Of those children with SDQ scores in the 'close to average' or 'slightly raised' ranges:
  - Twenty-one percent were seen by a psychologist and either had their psychological needs met by another service (tier 1b, 2%), received psychological input in response to a concern in clinic (tier 2b and 2c, 15%), or after clinic (tier 3, 4%).
  - Three percent were offered a separate psychology appointment (tier 4).

<sup>68</sup> Eligibility exclusions (not mutually exclusive): (Consent), children who died before the age of 5 years, with submucous cleft palates, and syndromic children.

- *This demonstrates that the SDQ does not identify all psychological concerns arising for children born with a cleft and their families at age five years, highlighting the importance of a face-to-face psychosocial screen and discussion.*

#### **3.9.4. SDQ ‘Total difficulties’ scale bands**

The SDQ has been recorded in CRANE for 486 children (49% of eligible cohort).

SDQ total scores were compared with population norms for the cohort<sup>69</sup> as a whole and were looked at by cleft type and sex. The patterns highlighted below need to be interpreted cautiously because the number of children in some of the groups is small, making it difficult to infer statistical or clinical significance. Furthermore, the population norms cover the age range of five to ten years and our cohort is at the extreme end of this range, all being age five years.

- Fifteen percent of children had SDQ total scores within the ‘high’ and ‘very high’ ranges combined (7% and 9% respectively). This compares with 10% (5% in each range) in the population norms.
- Eight percent of children born with a cleft lip only had SDQ total scores in the ‘high’ and ‘very high’ ranges, which is just below that expected from the population norms. Children born with all other cleft types had a higher proportion than population norms scoring in the ‘high’ and ‘very high’ ranges.
- Nine percent of girls had ‘high’ or ‘very high’ SDQ total scores, as compared with 19% of boys. These rates are higher than the corresponding 7.6% of girls and 12.2% of boys scoring in these ranges in the population norms. This pattern was true for all subscales with a higher proportion of boys than girls scoring in the ‘high’ and ‘very high’ ranges combined.

#### **3.9.5. Summary, considerations and limitations**

There was a considerable variation between cleft teams’ data completeness and a decision was taken, for this first year of reporting psychology data, to report on the national picture. The more detailed data will be used by the psychology Clinical Excellence Network (CEN) to gain a better understanding of the reasons for the variation.

With regards to the patient journey, where data have been supplied:

- Families were almost all seen for a face-to-face psychosocial screen before the target age of six years and the majority (63%) were seen for a psychosocial screen within the first year of the child’s life.
- Ninety-eight percent of children and families had their ‘psychosocial screen at age five’ before the age of six, meeting the target for the collection of outcome audit data.

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<sup>69</sup> The normative data in question were collected in 2000. Therefore, it may be that scores for the population norms would have increased over this period.

With regards to the level of psychological input (measured with the TIM) provided to families at age five when they were seen by a psychologist and psychosocial screen carried out:

- Fifty-three percent had no psychological concerns identified.
- Thirty-two percent received psychological input in the clinic (tier 2), of whom:
  - Seventy-seven percent received preventative input,
  - Fifty-four percent received input in response to a concern they raised, and
  - Thirty-two percent received both preventative input and input in response to a concern.
- Ten percent received psychological input after the clinic, with a minority receiving a psychology appointment.
- Cleft type did not predict those families who require or would benefit from an additional psychology appointment.

Looking at scores on the SDQ and comparing this with the level of psychological input provided to families at age five:

- For the majority children with an elevated SDQ score, the cleft team psychologist identified psychological concerns and provided psychological input to the family.
- The SDQ does not identify all psychological concerns arising for children born with a cleft and their families at age five years; however, 21% of children with lower scores on the SDQ had psychosocial concerns identified, highlighting the importance of a face-to-face psychosocial screen and discussion.

The SDQ Total scores identified a higher proportion of children with a cleft affecting the palate scoring in the 'high' and 'very high' ranges compared with population norms. A higher proportion of boys than girls scored in the 'high' and 'very high' ranges for the SDQ Total score and for all subscales. However, these findings should be considered with caution due to a number of factors detailed above.

### **3.10. Patient (and Parent) Reported Experience Measure (PREM) Feasibility Study**

A feasibility study to test Patient (and Parent) Reported Experience Measure (PREM) data collection was completed in 2017. Parents of children with a cleft of all ages (4 months and 23 years) and children, young people and adults with a cleft (aged 10y to 23y) were asked to complete questionnaires when they attended clinic. The questionnaires included the Friends and Family Test (FFT) and an Experience of Service Questionnaire (ESQ).

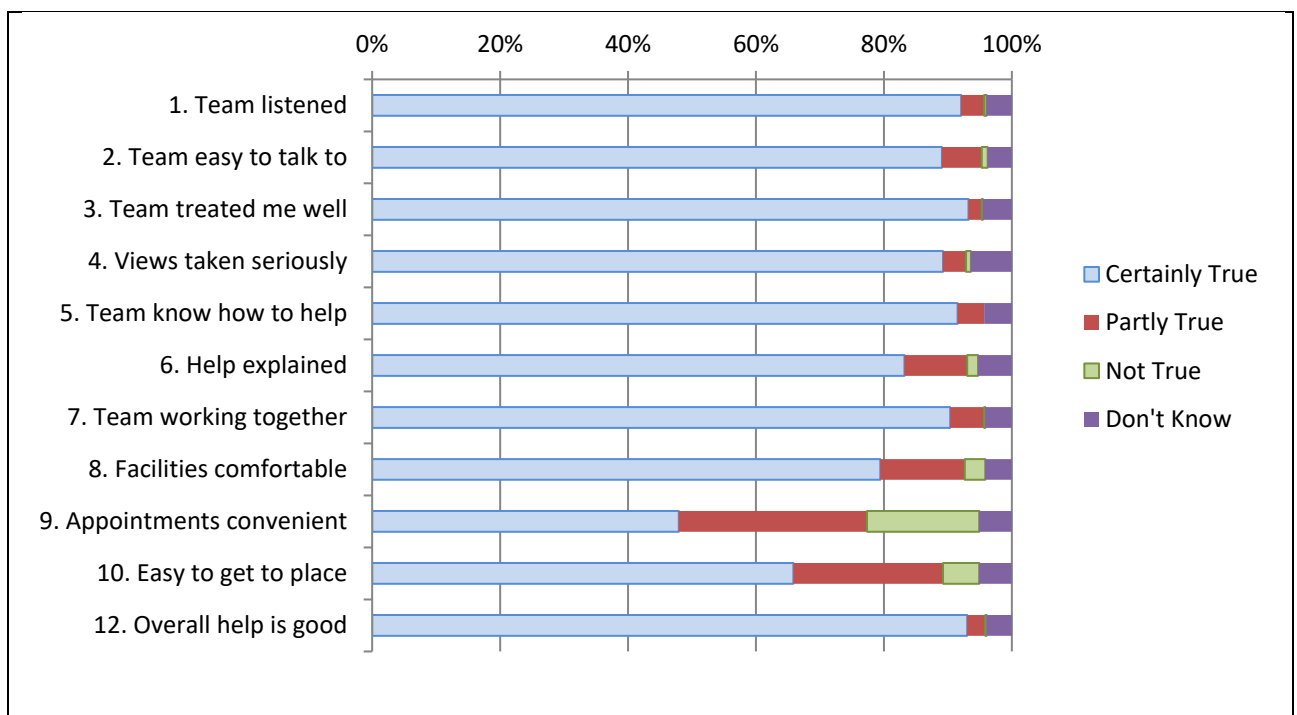
The FFT asks how likely people would be to recommend the service to a friend or family member. Looking at PREM data across Wales and England, there was a mean average Friends and Family Test (FFT) score of 81%, indicating high levels of satisfaction with the services received.



The highest scores were from parents of babies and children aged 4-30 months, who had a FFT score of 88%. There were also high scores from parents and children aged 9-13 years (FFT=82%) and those aged 18-23 years (FFT=86%). There were slightly lower scores from parents, children and young people aged 3-7 years (FFT=74%) and aged 15-17 years (FFT=74%). Further investigation is needed to understand the reasons for these differences.

The ESQ includes statements about a number of factors important to patient experience and asks, to what extent these statements are true. Responses from across England and Wales are shown in Figure 7 below.

**Figure 7.** Proportion of responses to each CHI-ESQ<sup>70</sup> item, according to each available answer category.



Note: CHI-ESQ item number 11 was not collected during this feasibility study as it requested the same information collected by the FFT questionnaire item (CHI-ESQ item 11. "If a friend needed similar help, I would recommend that he or she come here").

As a whole, cleft teams had very good feedback from people in relation to factors such as 'The team listened to me' and 'The team treated me well'. This suggests that cleft teams are doing well in their aims to be patient and parent centred, to work collaboratively with families and to work together as a multi-disciplinary team. The lowest agreement was with the statement 'Appointments are at a convenient time' and other factors such as how easy it is to get to appointments and how comfortable the facilities are had relatively low agreement. These are the factors that are less within the control of cleft teams themselves and more connected to hospital facilities and processes.

<sup>70</sup>The Experience of Service Questionnaire (CHI-ESQ) satisfaction assessment scales – developed by the Commission for Health Improvement (CHI).

Based on the input received from cleft teams throughout the study, from the Cleft Development Group (CDG) and the Craniofacial Society of Great Britain and Ireland (CFSGBI), the feasibility study team made the following recommendations:

1. Data should be collected on the patient experience of patients of all ages (with no age-restricted basis).
2. Patient experience data are to be reported by appropriate age groupings.
3. Data collection should not proceed with Friends and Family Test (FFT) measure. Instead, the missing CHI-ESQ question – similar to the FFT ('If a friend needed this sort of help, I would suggest to them to come here') – should be incorporated into data collection.
4. Data should be collected for all twelve CHI-ESQ components.
5. All cleft teams should agree to achieve a minimum response rate per year. Specifically, a response rate of 30 cases for small teams, and 60 for larger teams.
6. All cleft teams should agree to this data collection being captured/recoded in the CRANE Database; using electronic and local paper methods to start with, with the aim of moving to electronic methods only over time.
7. These PREM data should be reported on nationally for two to three years. After this time, and with the agreement of key stakeholders including the CDG, this data should be recorded on by centre/networks.

Please read the full PREM Feasibility Study report produced in August 2017 on [publications page of the CRANE Database website](#).

## 4. Outpatient hospital appointments at seven years of age in England

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The linkage of CRANE records to the National Pupil Database (NPD), at the individual level, has allowed us to explore educational achievement and special educational needs among children with a cleft lip and/or palate in England (see the 2014 and 2015 CRANE Annual Reports). More recently, we described school absence rates among the cleft population during National Curriculum Year 2, when children turn seven years of age and undergo their Key Stage (KS) 1 assessment (see the 2016 Annual Report). In the following section, we present data relating to hospital outpatient appointments attended during Year 2 of school and report the most common clinical specialties seen by children with a cleft lip and/or palate in England.

### 4.1. Introduction

In order for children to fulfil their academic potential, they need to attend school regularly to benefit from their education. Missing lessons leaves pupils vulnerable to falling behind, and children with poor attendance tend to achieve less in both primary and secondary school<sup>71,72,73,74</sup>. Our previous research revealed that, in Year 2, 62% of children with a non-syndromic cleft missed at least one school session for medical or dental appointments, and, overall, 0.8% of all possible school sessions were missed for such appointments. This equates to approximately 2.4 school sessions per child in Year 2 and is almost three times higher than the corresponding figure for the general population.

Using CRANE data linked with NPD, Hospital Episode Statistics (HES) and HES outpatient data, our aim was to explore the number and type of hospital appointments that children with a non-syndromic cleft attend during the Key Stage 1 assessment year. We describe the main specialties seen and examine differences in appointments between the four main cleft types and the 13 cleft units in England. For information on how hospital appointment data were analysed, please refer to the Hospital outpatient appointment section within the Methods chapter.

### 4.2. Outpatient hospital appointments according to type of cleft

There were 6,194 CRANE-registered children born from 2000 onwards who were matched to NPD records (87% linkage rate). Of these, 4,928 had KS1 assessments and were in Year 2 between 2006/07 and 2013/14. In total, there were 12,909 appointments attended by 3,189 children with a

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<sup>71</sup> Department for Education. *The link between absence and attainment at KS2 and KS4. 2012/13 academic year*. London: Department for Education. 2015.

<sup>72</sup> Arthurs N, Patterson J, Bentley A. Achievement for Students Who are Persistently Absent: Missing School, Missing Out? *The Urban Review*, 2014; 46(5):860-76. <http://dx.doi.org/10.1007/s11256-014-0307-4>

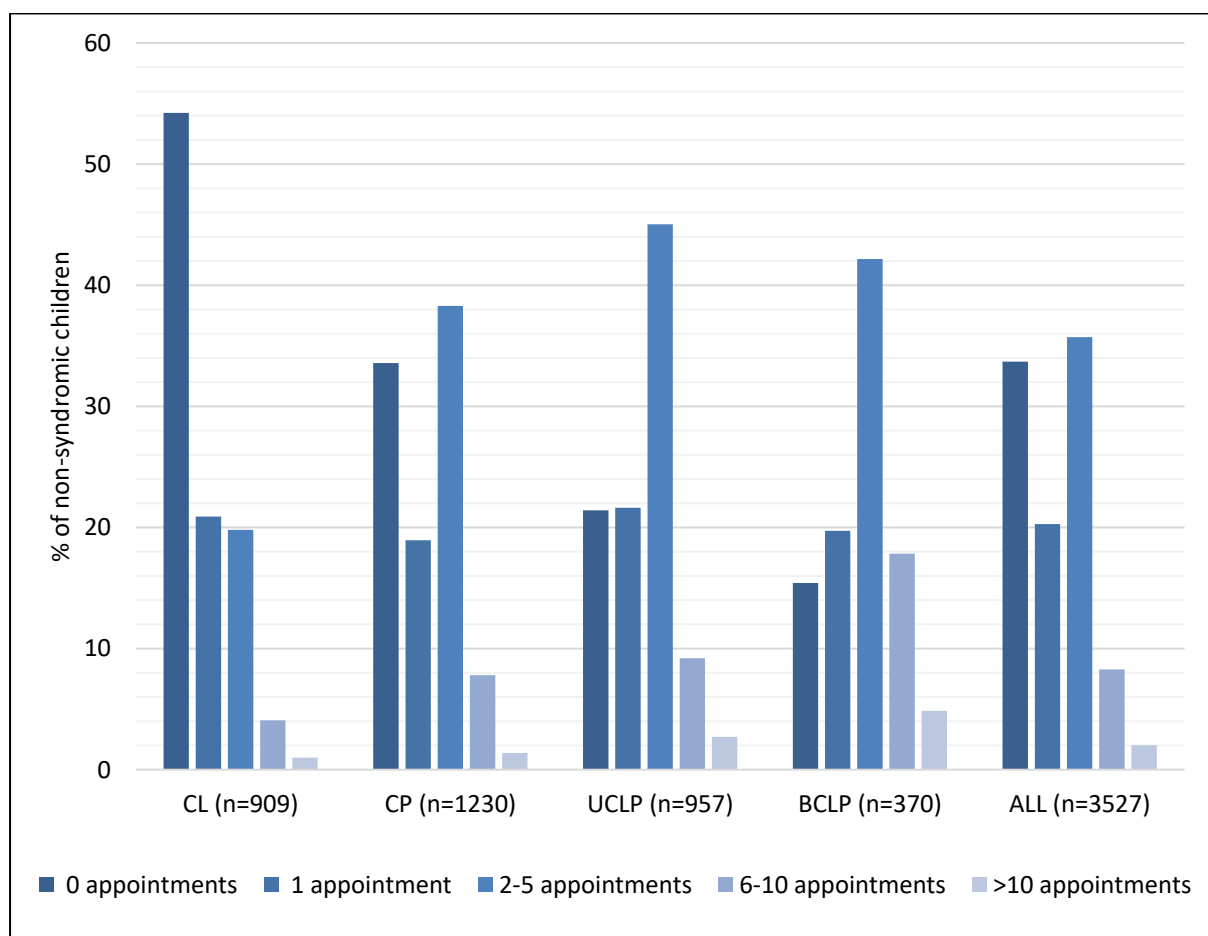
<sup>73</sup> Gottfried MA. The Detrimental Effects of Missing School: Evidence from Urban Siblings. *American Journal of Education*, 2011; 117(2):147-82. <http://www.jstor.org/stable/10.1086/657886>

<sup>74</sup> Hancock, K. J., Shepherd, C. C. J., Lawrence, D., and Zubrick, S. R. (2013). *Student attendance and educational outcomes: Every day counts*. Report for the Department of Education, Employment and Workplace Relations, Canberra.

cleft (64.7% of cohort) during Year 2 of school. Approximately one third of the children had no hospital appointments during Year 2. The number of appointments attended in the 12-month period (1 September to 31 August) ranged from 0 to 59.

There were 3,527 children with a non-syndromic cleft in the cohort. Among this group, there were a total of 7,754 appointments attended by 2,290 children (64.9% of non-syndromic children in the cohort) during Year 2 of school. Attended appointments ranged from 0 to 36 during the 12-month period. The number of attended appointments varied significantly according to type of cleft ( $p < 0.0001$ ). Figure 8 shows the proportion of children within each appointment volume category according to their cleft type (see [Appendix 9](#) for tables of data used to create the figures in this chapter). The majority (54%) of those with a CL did not attend any hospital appointments; this was the case for just 15% of those with a BCLP. Figure 8 also shows that a greater proportion of children attended more hospital appointments with each increasing cleft type severity group. The majority of children with a cleft affecting both the lip and palate had between two and five appointments during the academic year in which they turn seven years of age.

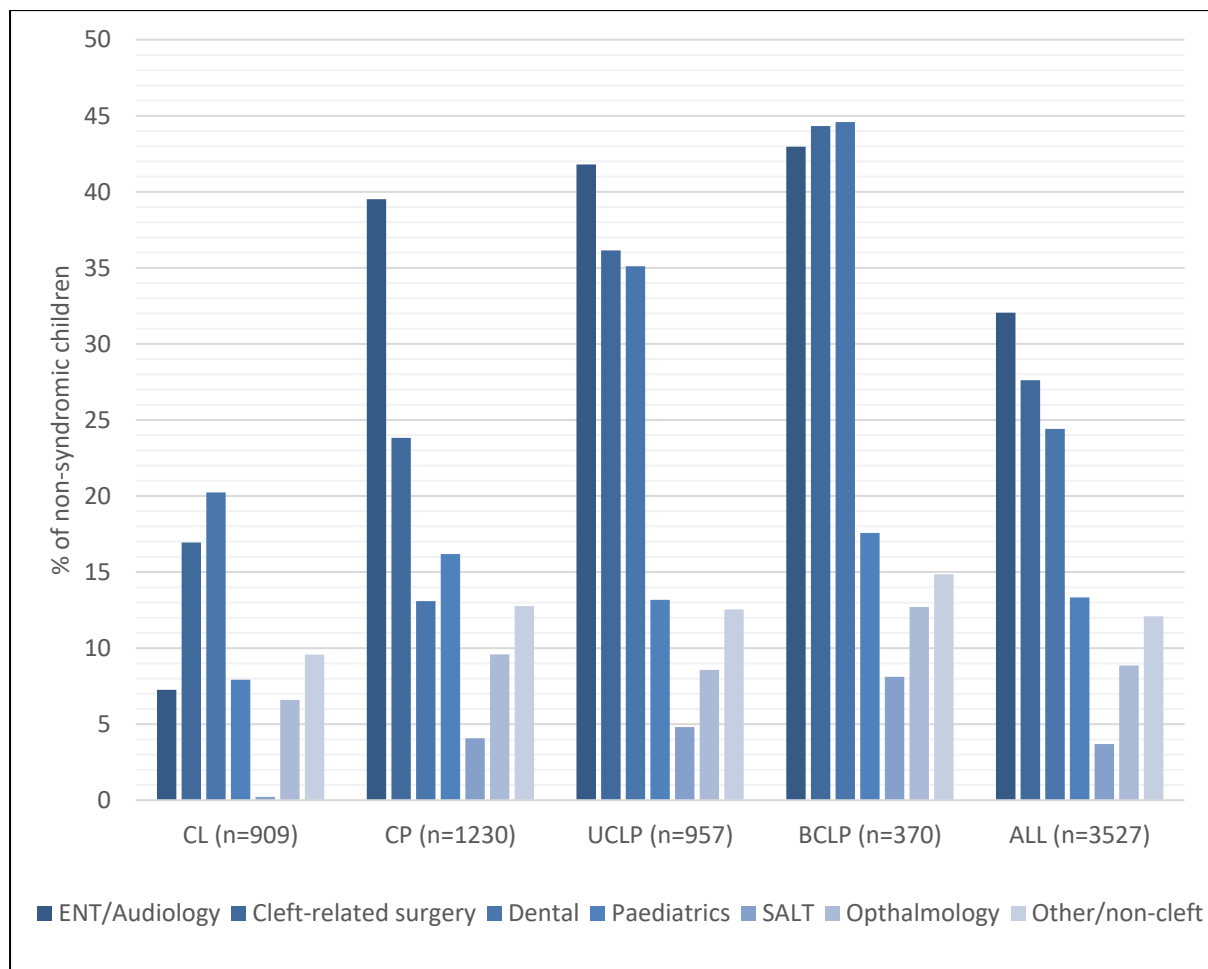
**Figure 8.** Percentage of children with a non-syndromic cleft according to cleft type and how many hospital outpatient appointments they attended during school Year 2



**Notes:** 61 children do not have a specified cleft type, hence the total number is not equal to the sum of the four cleft type groups. CL, cleft lip; CP, cleft palate; UCLP, unilateral cleft lip and palate; BCLP, bilateral cleft lip and palate

The type of specialties seen by children with a non-syndromic cleft lip and/or palate in hospital outpatient appointments during Year 2 of school were examined. Figure 9 reflects the burden of hospital appointments for children with a non-syndromic cleft. In general, the proportion of children seeing the specialties shown in Figure 9 increased with each increasing cleft type severity group. An exception to this rule were dental outpatient appointments, which were more common among children with a cleft affecting the lip than those with a CP. It was most common for children with a cleft affecting the palate to see a specialist under ear, nose and throat (ENT) or audiology. Between 39.5% (CP) and 43.0% (BCLP) had these appointments around the age of seven years.

**Figure 9.** Percentage of children with a non-syndromic cleft seeing each specialty in hospital outpatient appointments during school Year 2, according to cleft type

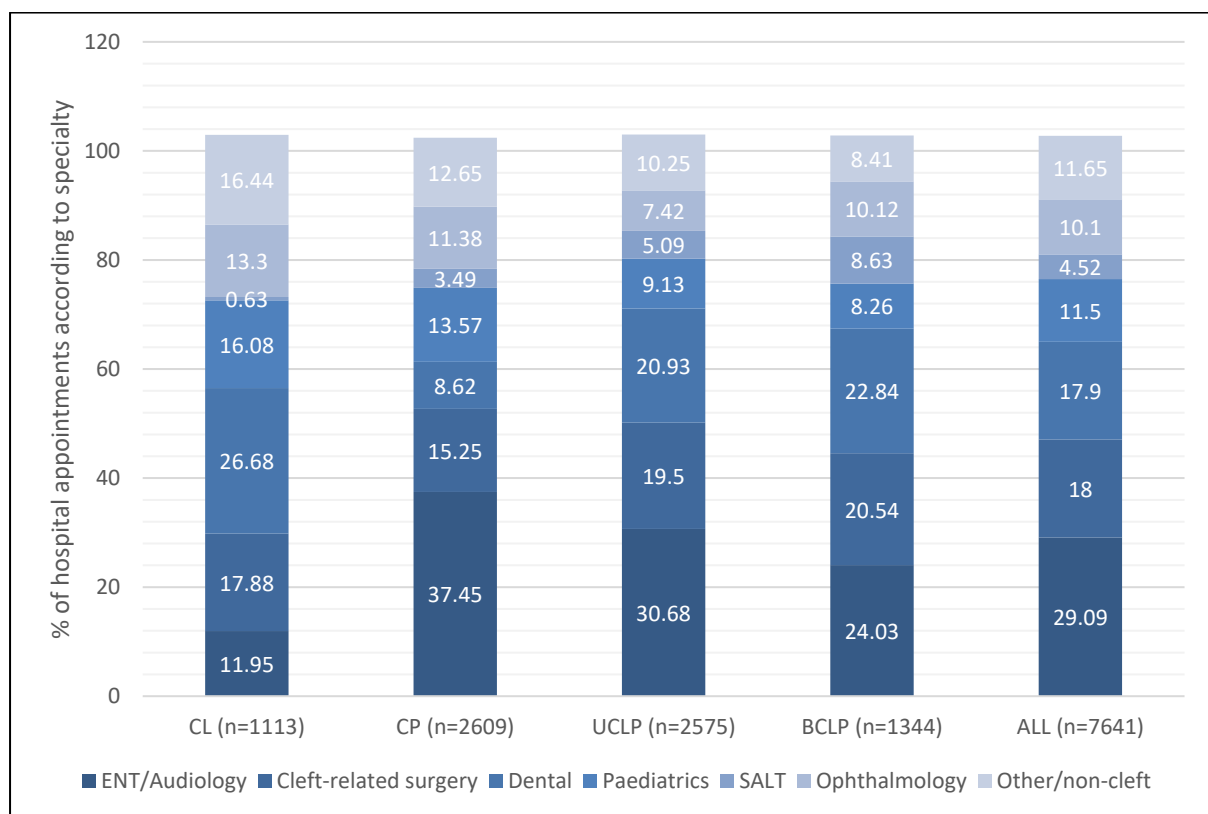


**Notes:** 61 children do not have a specified cleft type, hence the total number is not equal to the sum of the four cleft type groups. CL, cleft lip; CP, cleft palate; UCLP, unilateral cleft lip and palate; BCLP, bilateral cleft lip and palate; ENT, ear, nose and throat; SLT, speech and language therapy

The second most common category was cleft-related surgery appointments, which were attended by 27.6% of the non-syndromic cleft cohort. This proportion ranged from 16.9% among children with a cleft lip to 44.3% among those with a BCLP. Secondary care dental appointments were also fairly common among those with a cleft affecting the lip. The proportion ranged from 20.4% among

children with a CL to 44.6% among those with a BCLP. Sixteen percent of children with a CP attended dental outpatient appointments. Overall, 13% of non-syndromic children attended appointments under Paediatrics; this ranged from 7.9% in the CL group to 17.6% in the BCLP group. Just 3.7% of children attended speech and language therapy (SLT) appointments in hospital, although this figure is likely to substantially under-represent the proportion of children receiving SLT as this service is more commonly provided in the community. Ophthalmology appointments were attended by 6.6% of children with a CL. This proportion increased to 12.7% among those with a BCLP. Overall 12.0% of children had appointments under other, non-cleft-related, specialties during the academic year in which they turned seven years.

**Figure 10.** Proportion of all hospital appointments attended by non-syndromic children during school Year 2, according to cleft type and the various treating specialties \*



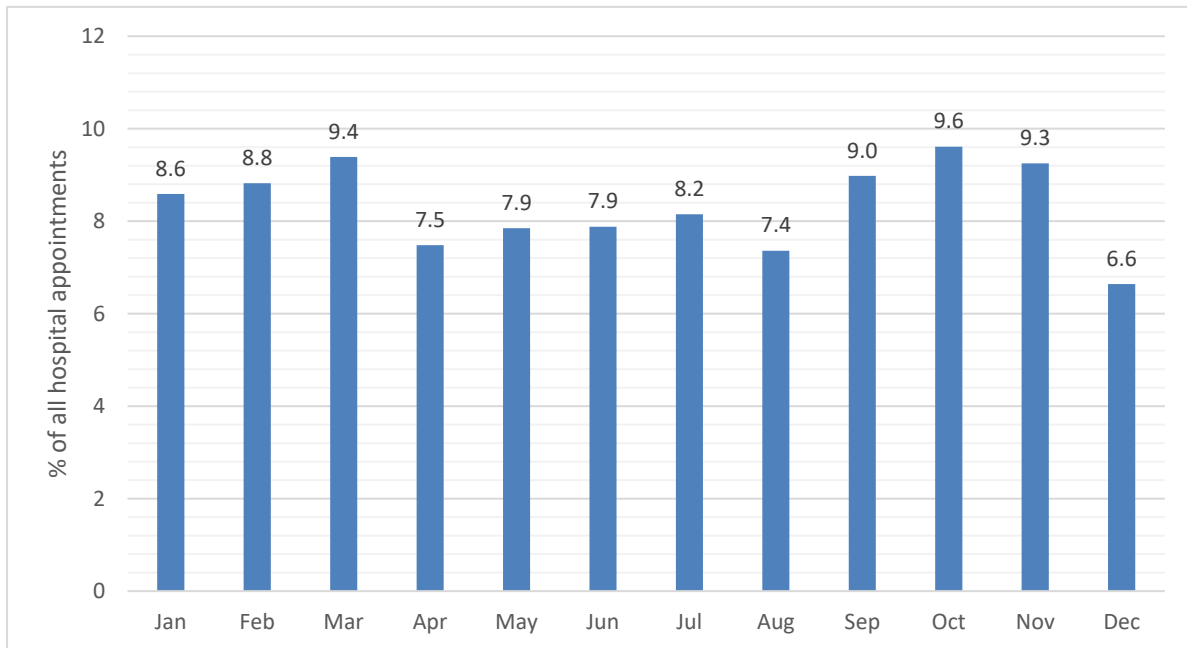
**Notes:** \* 2.75% appointments have more than one specialty recorded, hence totals are >100%; CL, cleft lip; CP, cleft palate; UCLP, unilateral cleft lip and palate; BCLP, bilateral cleft lip and palate; ENT, ear, nose and throat; SLT, speech and language therapy

Figure 10 reflects the burden of hospital outpatient care on services and shows the proportion of all hospital appointments among children with a non-syndromic cleft made up by the various treating specialties. Overall, 29% of all outpatient appointments attended by children with a non-syndromic cleft around the age of seven years are provided by ENT or audiology. This proportion was greatest, at 37.5% among those with a CP. For children with a CL, the most common type of appointments were dental, which accounted for 26.7% of all appointments provided for the subgroup. Outpatient

SLT and ophthalmology appointments represented the smallest proportion of appointments for children with a cleft lip and/or palate.

Figure 11 shows the distribution of appointments throughout the calendar year. December and August had the fewest appointments, indicating that children around the age of seven are most likely to attend hospital appointments during the school term time, which has implications for school attendance.

**Figure 11.** Percentage of annual hospital appointments attended by children with a non-syndromic cleft during year 2 of school according to calendar month

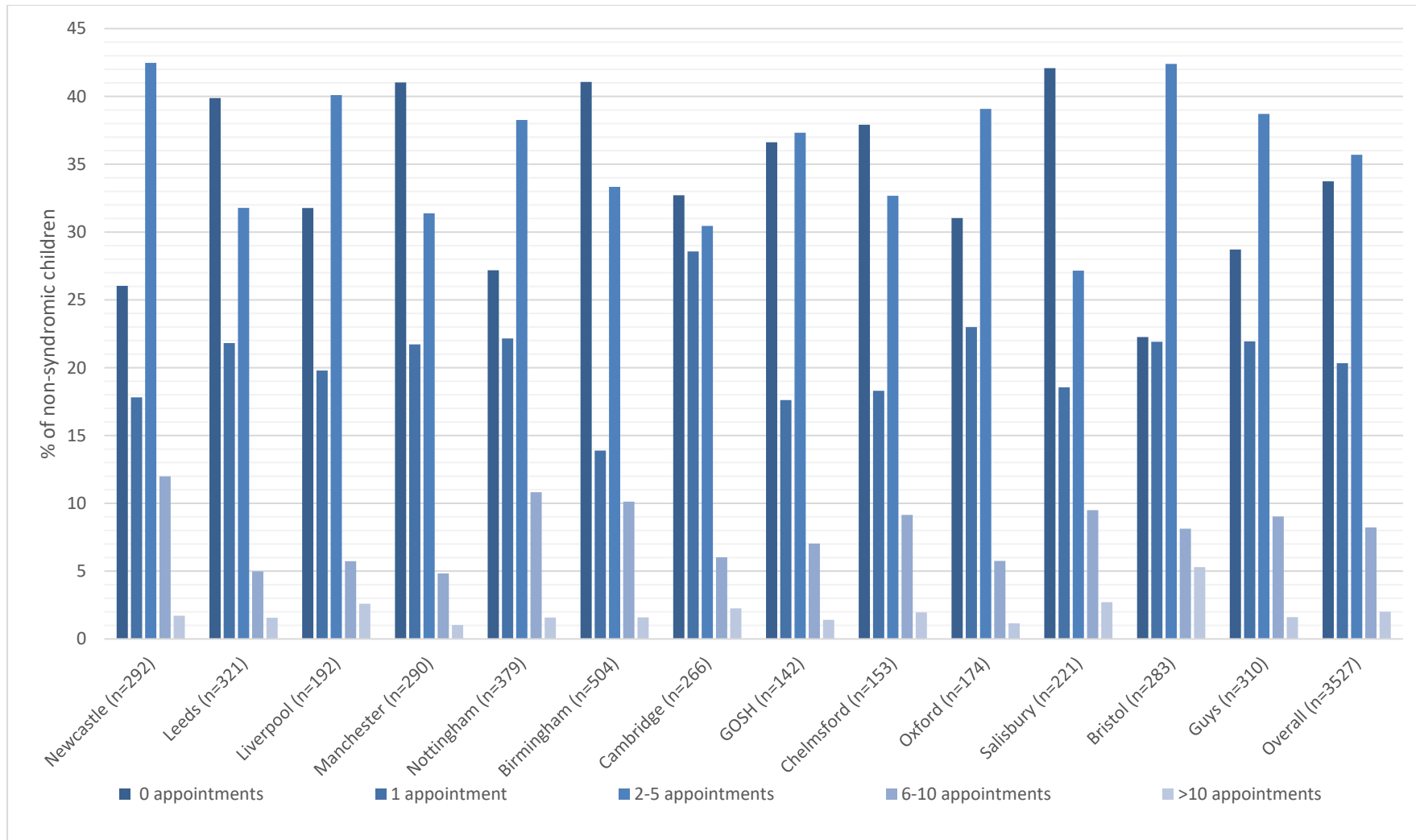


### 4.3. Outpatient hospital appointments according to cleft Unit

Data were analysed according to the 13 Cleft Units in England. The number of children within the cohort under each Unit during school Year 2, between the academic years 2006/07 and 2013/2014, ranged from 174 in Oxford to 504 in Birmingham. The data presented are reported according to the registering cleft Unit and do not necessarily reflect the hospital where the appointments occurred.

Figure 12 shows a variation in the proportion of children not attending any hospital appointments during school Year 2. This proportion ranged from 22.3% for those registered in CRANE by Bristol to 42.1% registered by Salisbury (see Appendix 9 for data). While Bristol had the lowest proportion of children without any hospital appointments around the age of seven years, they had the highest proportion (5.3%) of children with >10 appointments during school Year 2. This is 2.6 times higher than the national average of 2.1%. Just 1.0% of CRANE patients registered by Manchester had >10 appointments in the year that they turned seven, which was the lowest proportion among the cleft Units. Manchester also had the lowest proportion (4.8%) of children with 6-10 appointments during school Year 2, while Newcastle had the highest proportion among the cleft Units at 12.0%.

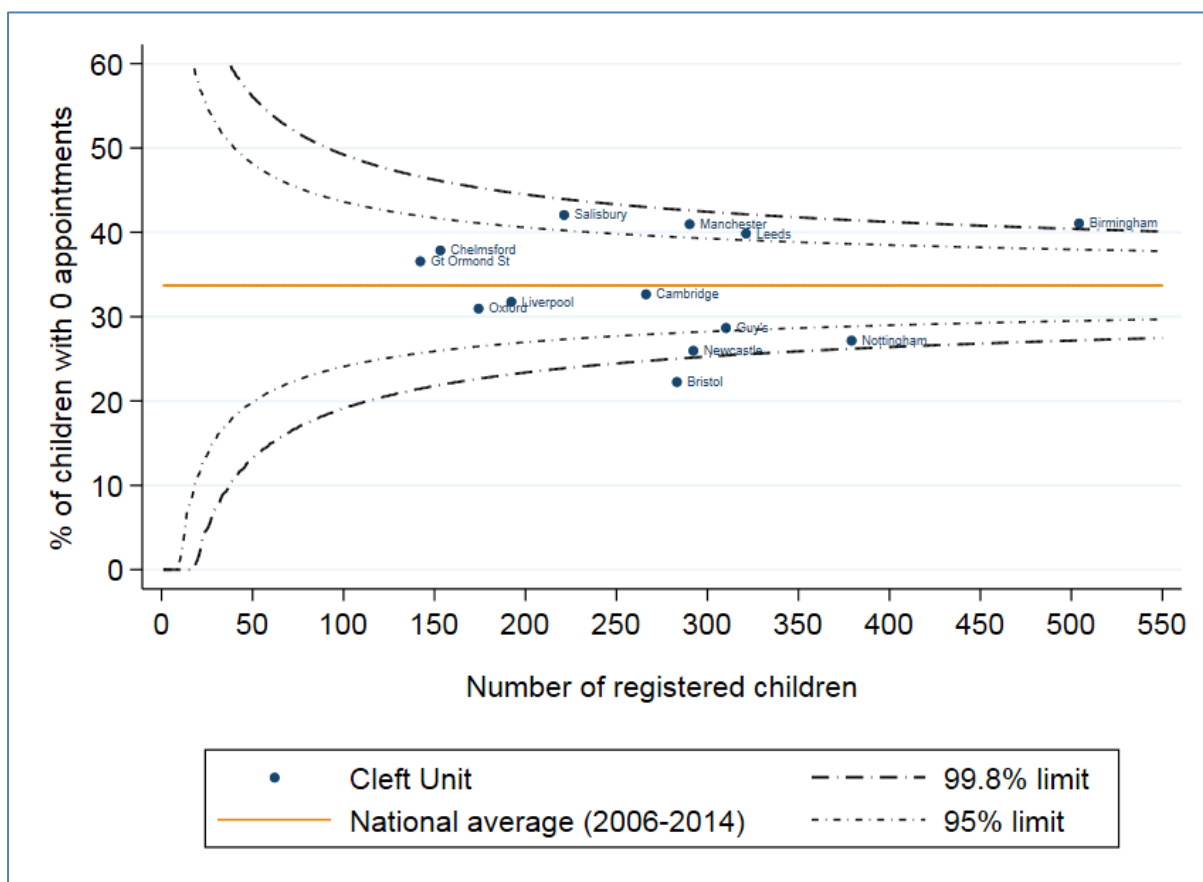
**Figure 12.** Percentage of children with a non-syndromic cleft according to cleft Unit and how many hospital outpatient appointments they attended during school Year 2





The funnel plot in Figure 13 shows the regional variation in the proportion of children without any hospital appointments during Year 2 of school according to the number of children registered at each cleft unit. It is centred on the national average of 33.7% for children with a non-syndromic cleft. The funnel plot shows that Birmingham had a rate above the upper 99.8% control limit while Bristol had a rate that was below the lower 99.8% control limit. Salisbury, Manchester and Leeds had rates above the upper 95% control limit, whereas Newcastle and Nottingham had rates below the lower 95% limit, indicating these are significantly different from the overall mean. All other units had rates that were within control limits and are therefore not significantly different to the overall mean.

**Figure 13.** Funnel plot showing percentage of children with a non-syndromic cleft within each unit who had 0 outpatient appointments during Year 2 of school\*



Figures 14 to 16 show funnel plots displaying the proportion of children with a non-syndromic cleft seeing cleft-related specialties at least once during their Year 2 of school according to cleft unit (see Appendix 9 for data). Figure 14 reveals a large variation between units in the proportion of children having at least one appointment under Ear, nose and throat (ENT) or audiology. Three units had rates that were outside the 99.8% control limits, indicating that their rates are significantly different to the overall mean of 32.1%. Newcastle had the highest proportion (50.3%) of children seeing ENT or audiology, while Cambridge and Manchester had rates of 22.9% and 20.0%, respectively, which were below the lower limit.

**Figure 14.** Funnel plot showing percentage of children with a non-syndromic cleft within each unit who had at least one appointment under Ear, nose or throat or Audiology during Year 2 of school

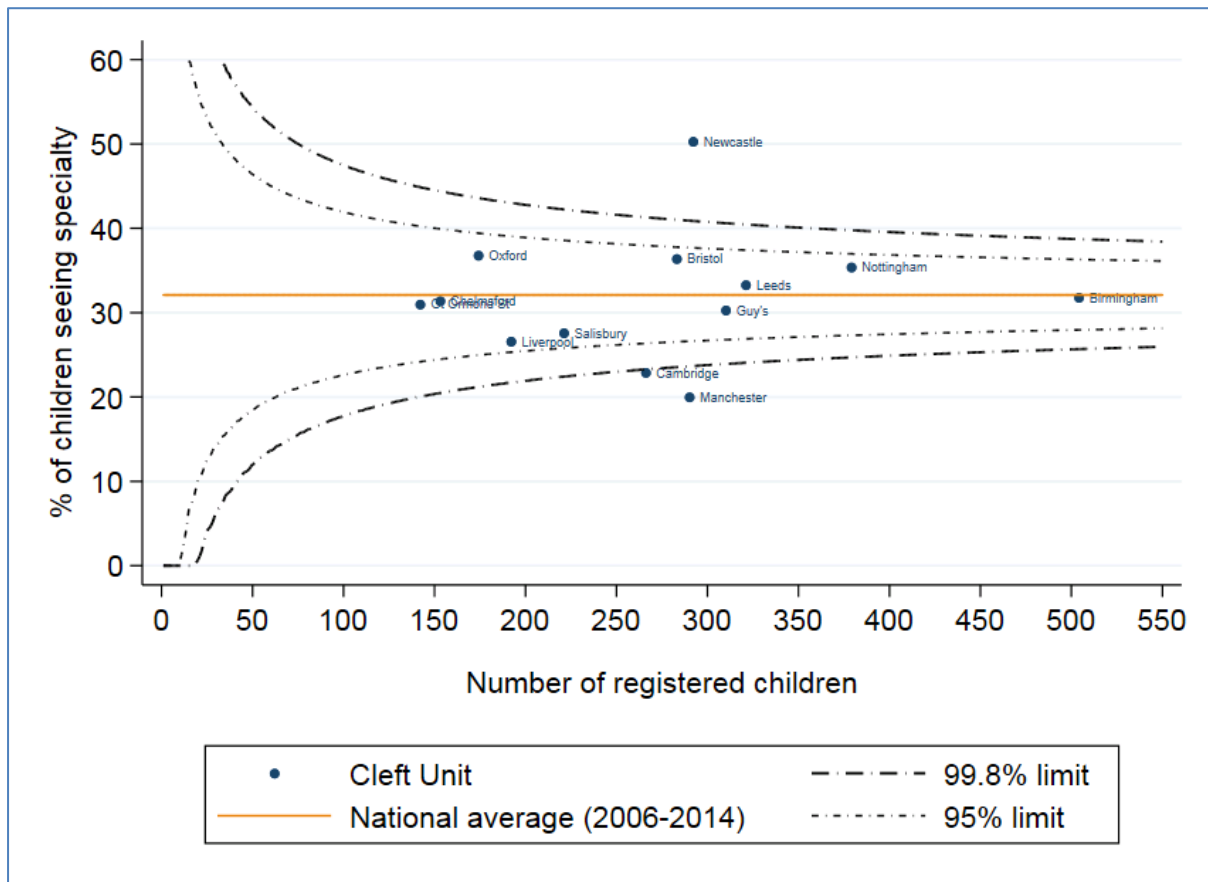


Figure 15, again, shows wide variation between units in the proportion of children having at least one outpatient appointment under cleft-related surgery. The funnel is centred around the overall mean of 27.6%. Seven out of the 13 units were outside the 95% control limits, while four were outside the 99.8% limits. Leeds had the lowest rate, at 5.6%, while Guys’ had the highest proportion (41.3%) of registered children with cleft-related surgery appointments.

The final funnel plot, in Figure 16, highlights the regional variation in service provision of dental appointments at hospital in Year 2 of school. Only four units were within the 95% control limits based around the national mean proportion of 24.3%. Bristol had a rate a rate of 47.4%, which was almost twice as high as the national rate, while Manchester, Chelmsford, Oxford and Birmingham all had fairly low rates of between 11% and 13%.

For children with a non-syndromic cleft, appointments under paediatrics, ophthalmology and other, non-cleft related, specialties were relatively uncommon; the range seen between Units was therefore not as substantial when compared with the cleft-related specialties. Appendix 9 shows the data for all categories of appointments by unit.

**Figure 15.** Funnel plot showing percentage of children with a non-syndromic cleft within each unit who had at least one appointment under cleft-related surgery during Year 2 of school

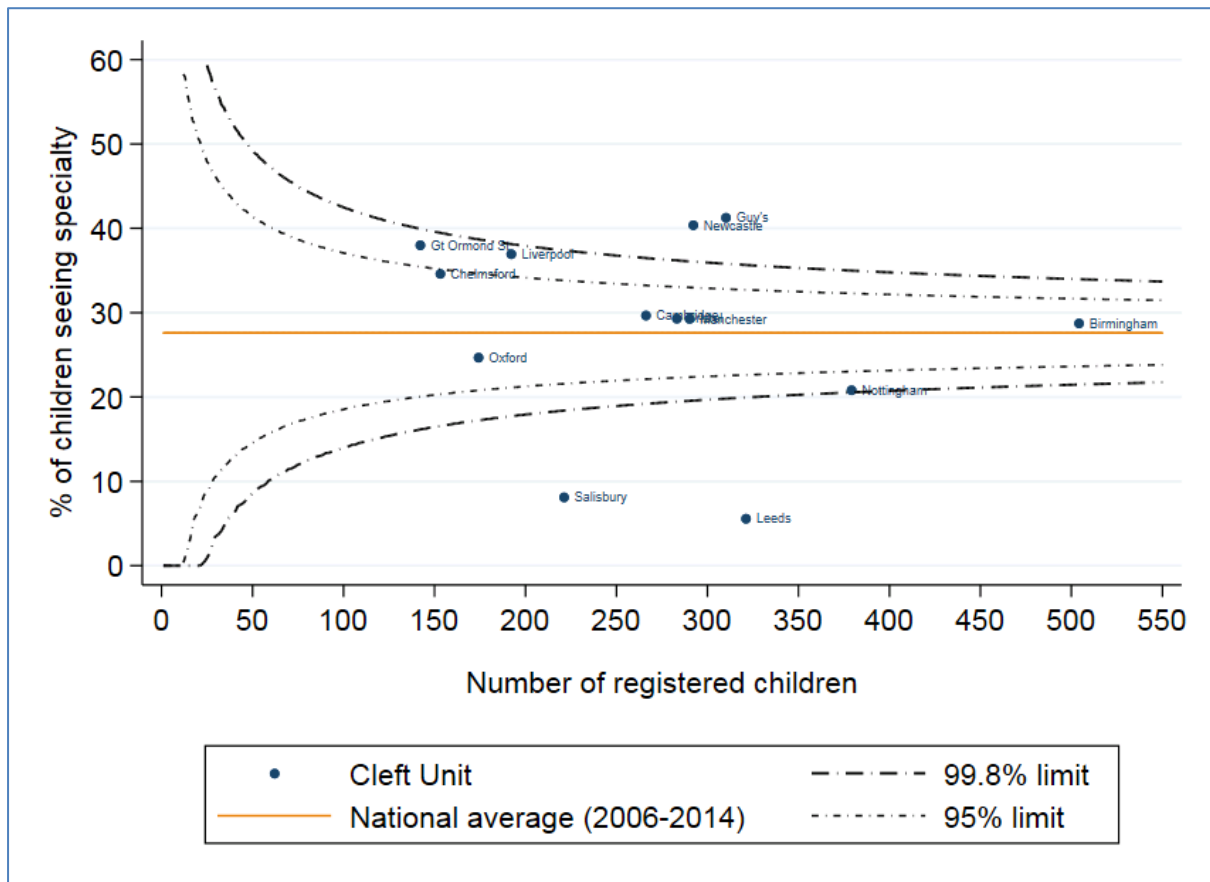
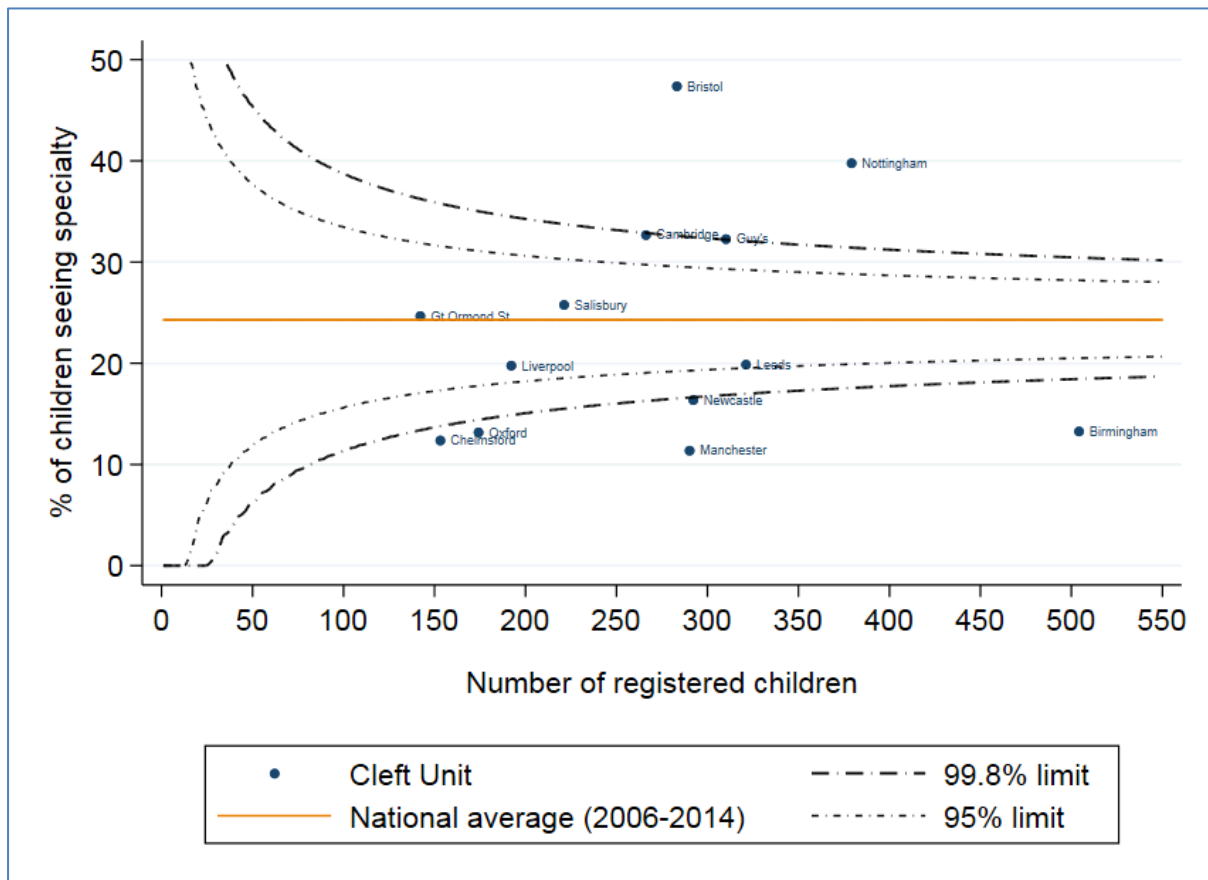


Figure 17 reflects the burden of hospital outpatient care on particular specialties. The chart shows the proportion of all hospital appointments among children with a non-syndromic cleft, around the age of seven years, made up by the various treating specialties. Overall, the largest proportion of all appointments were those for ENT and audiology. Approximately 35% of all appointments attended by non-syndromic children registered by Newcastle, Leeds, Birmingham and Oxford were for ENT or audiology. Cleft surgery-related outpatient appointments represented a substantial proportion (approximately 28%) of all appointments for children under Manchester, Great Ormond Street and Guy’s. Conversely, the corresponding figure for Leeds was just 3.7%. The greatest proportion of outpatient appointments for children under Nottingham, Cambridge and Bristol were dental appointments.

**Figure 16.** Funnel plot showing percentage of children with a non-syndromic cleft who had at least one appointment under Dental during Year 2 of school, according to the number of children registered within each unit.

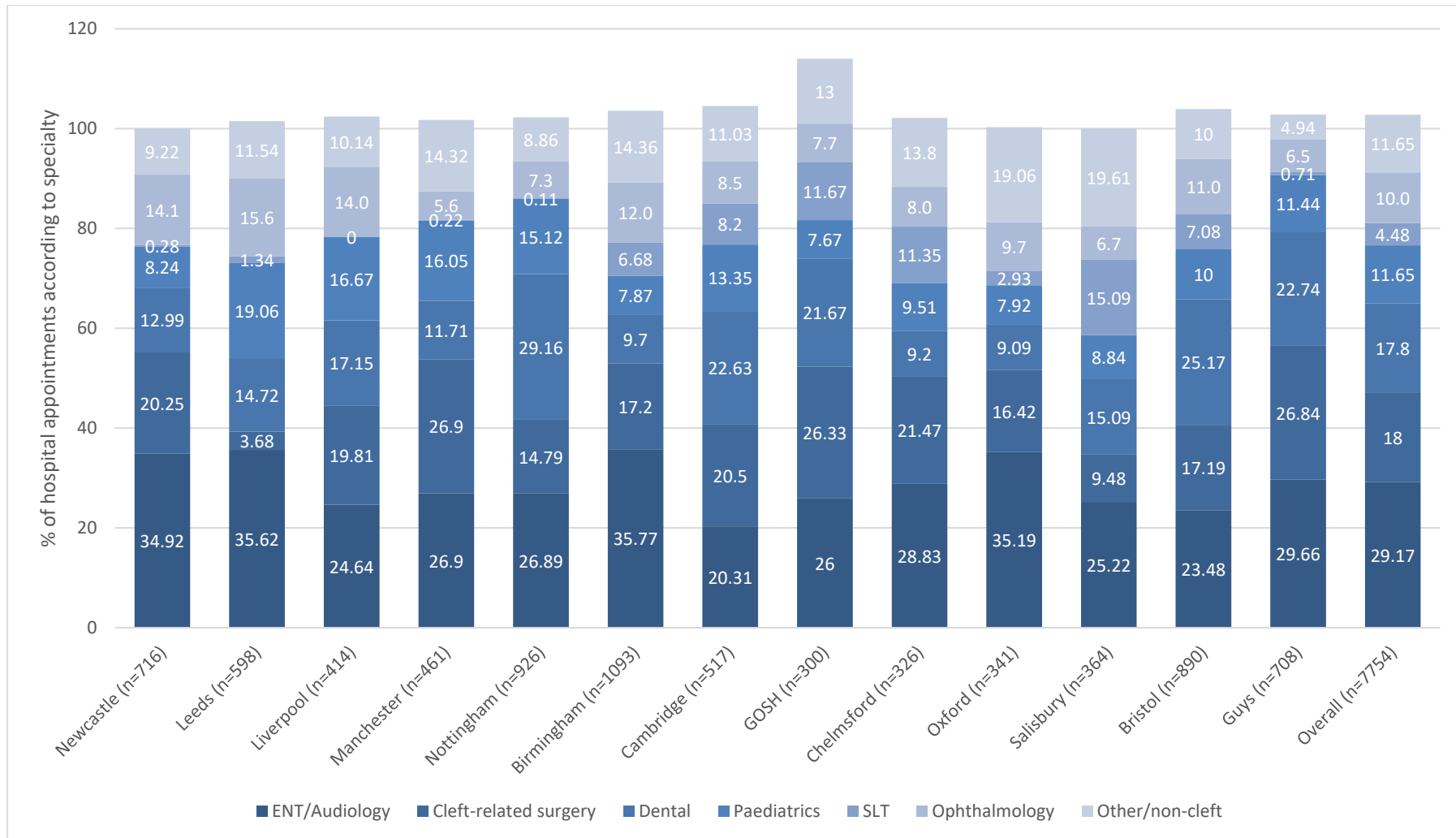


#### 4.4. Summary

For the first time, hospital outpatient data have been explored for a cohort of school children with a non-syndromic cleft. These data show substantial differences between the four main cleft types in the number and type of hospital appointments attended during Year 2 of school, when most children turn seven years of age and undergo their Key Stage 1 assessment. A clear trend was observed for an increasing number of appointments with increasing cleft-type severity. The burden of hospital appointments for children with a non-syndromic cleft has been quantified according to each main treating specialty. We have shown that a substantial proportion of children with a cleft lip and palate will attend hospital appointments under ENT and audiology, cleft-related surgery and dentistry around the age of seven.

The presented data have revealed that cleft type is not the only determining factor in the number or type of appointments attended. Substantial regional differences exist in outpatient service provision for children with a non-syndromic cleft. Differences in appointment volume and appointment specialty type were apparent and the burden of care for relevant cleft specialties varied considerably between the 13 cleft Units.

**Figure 17.** Proportion of all hospital appointments attended by non-syndromic children during school Year 2, according to cleft Unit and the various treating specialties\*



**Notes:** \* 2.75% appointments have more than one specialty recorded, hence totals are >100% for some Units; ENT, ear nose and throat; SLT, speech and language therapy

A limitation of this analysis is that these data reflect appointment attendance during one particular school year and are, in essence, a snapshot in time. The differences observed in the current dataset may vary in a different year or, indeed, level out if we combine several school years of data. Another limitation includes the possibility that cleft outpatient service provision has changed since the study period.

While we have aimed to quantify the burden of hospital outpatient appointment attendance for children with a cleft at an age where they undergo their Key Stage 1 school assessment, some children with a cleft attend speech and language therapy in the community and some children from the cohort may also access primary care dental services. Our data are therefore likely to underrepresent the true burden of health care appointments faced by children with a cleft in England.

We have highlighted differences in appointments between cleft groups and cleft Units. However, it is not possible to determine whether the advantages of attending appointments and accessing various cleft-related specialties outweighs the disadvantages of missing school. Future analyses will examine the impact of school absence on academic attainment within the cleft population.

# 5. Development of CRANE Database and future directions

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## 5.1. Future development of the CRANE Database and website

We intend to continue work on specifying data collection of the following sections for the database, as proposed by our stakeholders:

- LAHSAL data collection items will be changed to collect LAHSHAL data to increase the phenotypic data available for analysis and linkage to other projects.
- Surgical section / items will be introduced to allow the collection of data on multiple surgeries.
- Dental Defects of Enamel (DDE) items (at five and ten years) will be introduced, as proposed by the Paediatric Dental Clinical Excellence Network (CEN) of CFSGBI.

## 5.2. Scotland

Scotland service managers have confirmed their intention to submit data to the CRANE Database for the first time. We are currently engaged in the process of setting up the necessary permissions for sharing data with Scotland for a start date of 1 April 2019. This will be the first time the project will achieve full UK coverage and is a significant step forward.

## 5.3. Outcome measures

Despite the progress made, the Database is hampered by the lack of agreed measures which have been shown to be valid and reliable in assessing the outcomes of cleft care. We were asked to see if outcomes could be agreed for older children and young adults by the Clinical Directors group at the Newcastle CFSGBI conference previously. We are running a multiphase Delphi consultation using different methods of engagement to develop consensus and identify valid and robust measures.

## 5.4. Data sources and future analyses

### 5.4.1. National Pupil Database (NPD)

We are continuing our work with NPD and CRANE-HES-linked data and are in the process of applying for a new linkage following changes to the process by the DoE after GDPR introduction this year.

Future analyses will involve exploring in more detail children's educational attainment at Key Stage 2, when children are 11 years of age. Tracking children's longitudinal educational attainment across different assessments as they age will allow us to study whether attainment gaps persist and to what extent, or whether children with a cleft do catch up with their peers in the general population.

Future analyses will also aim to examine the correlation between educational outcomes and treatment outcomes recorded in CRANE, such as speech quality, and we are interested in exploring whether there are

aspects of the cleft treatment pathway, such as timing of repair and the number and type of outpatient appointments, that may be associated with observed differences in educational outcomes within the cleft cohort.

#### 5.4.2. Hospital Episode Statistics (HES)

We are in the process of applying to NHS Digital to allow linkage of CRANE data and improve the data quality of our identifiers, which helps with linkage to other resources such as the NPD. We are requesting that this updated HES extract contain hospital data from January 2000 up to March 2018.

This is a new approach and a separate application to that usually made as part of the Clinical Effectiveness Unit's application. This is because the CEU now only receives a rolling extract containing data for the most recent 10 calendar years<sup>75</sup>. This is no longer fit for CRANE's purposes, as we have been collecting data on births and registrations since 2000.

The current (new) CRANE application to NHS Digital will allow us to refresh our analyses involving HES data since the last HES-CRANE linkage exercise was conducted in March 2013, such as the analyses involving the NPD, mortality, secondary speech surgery, and grommets.

#### 5.4.3. Newborn Hearing Screening Programme (NHSP)

We have approval for linkage between our CRANE Database and the Newborn Hearing Screening Programme (NHSP)<sup>76</sup> data – via Public Health England (PHE) – with the purpose of looking at the relationship between clefts and Permanent Childhood Hearing Impairment (PCHI) and the effect of PCHI on children's outcomes. We are currently awaiting confirmation of resource allocation at PHE to undertake the linkage process.

### 5.5. Quality Dashboard

The CRANE project team have submitted data for the 2016/17, 2017/18 and 2018/19 quality dashboards. This was done for the following five out of the six items requested, two of which were new requests (CLP01 and CLP02):

- Measure Number CLP00: The number of CRANE-registered children born within a specified quarter of the calendar year (refreshed every quarter).
- Measure Number CLP01: The number of Parents contacted by a Cleft team Clinical Nurse Specialist (CNS) within 24 hours of referral with an antenatal diagnosis of Cleft Lip and/or Palate – born within a specified quarter of the calendar year (refreshed every quarter).

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<sup>75</sup> This is a result of NHS Digital refining their policies, in light of the General Data Protection Regulation (GDPR) that came into force in May 2018.

<sup>76</sup> <http://hearing.screening.nhs.uk/>



- Measure Number CLP02: The number of Parents receiving visit from a Cleft team CNS within 24 hours of first referral (provided the child has not reached the age of one year) – born within a specified quarter of the calendar year (refreshed every quarter).
- Measure Number CLP06: The number of five-year old children with a decayed, missing and filled teeth (dmft) index score, as a percentage of all five-year old children (refreshed annually).
- Measure Number CLP09: The number of five-year-old children with five-year old index scores 1 or 2 (as indicator of maxillary growth in patients with complete UCLP<sup>77</sup>) – as a percentage of the number of five-year old children with a five-year old index score (refreshed annually) [previously numbered CLP08].

The sixth item requested by Methods pertains to speech data, and was provided directly by the centres:

- Measure Number CLP07: The number of five-year old children with green Cleft Audit Protocol for Speech – Augmented CAPS-A scores – (who have speech within normal range) as a percentage of the number of five-year old children with a CAPS-A score (refreshed annually).

Future productions of Quality Dashboard CRANE tables have been confirmed – potentially including speech data (future dates have yet to be agreed).

## 5.6. CRANE Communications

### 5.6.1. Dissemination of 2018 findings

- Publication of the Annual Report will be announced via our regular Newsletter, which will be circulated in December, and it will be available on our website.
- We will also work with our close collaborators, such as the CFSGBI and CLAPA, to expand the reach of our eNewsletter (and the report).
- *A Summary of Findings for Patients and Parents/Carers* from this 2018 Annual Report will be produced in collaboration with CLAPA, with the aim of publishing this in close timeline to the main report.

### 5.6.2. Publications and presentations related to the CRANE Database

#### Oral presentation(s)

- CFSGBI Annual Scientific Conference April 2018, Birmingham
- Confirmed invited speaker and member of the Scientific committee at the European Cleft Palate Craniofacial Association, Utrecht, Netherlands meeting 12-15 June 2019 presenting on national outcome data collection in the UK

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<sup>77</sup> Atack NE, Hathorn IS, Semb G, Dowell T and Sandy JR. A new index for assessing surgical outcome in unilateral cleft lip and palate subjects aged five: reproducibility and validity. *Cleft Palate Craniofac J.* 1997 May;34(3):242-6.

## 6. Conclusions

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This Annual Report presents national-level data on children born with a cleft lip and/or palate in England, Wales and Northern Ireland.

A total of 1,068 children born with a cleft in 2017 had been registered on CRANE at the time of preparing this report. This equates to an incidence of approximately one in every 657 live births in England, Wales and Northern Ireland<sup>78</sup>.

Children can now be registered with CRANE prior to obtaining parental consent. However, consent must still be obtained so that complete outcomes data can be collected and reported by CRANE. The consent rate is very high among families who have been through the consent process, which is encouraging. In addition, all families of children born in 2017 had a record of being approached for consent at the time of preparing this report. This is extremely positive, as consent is essential for the collection of a full dataset and the linkage to other datasets.

Following registration, the majority of units collect all the data items requested by CRANE. However, the reporting of some data, in particular outcomes at five years of age, is variable between units<sup>79</sup>. CRANE will continue to explore ways to improve communication and links with units to improve the submission of data in the future. Continued development of the CRANE Database and Website is expected to play a key role in facilitating this (see [Chapter 5](#) for further detail on this).

Collecting and reporting outcomes among children with a cleft is important for evaluating treatment, drawing comparisons between different groups of patients, providing information to patients and parents, and for planning future services. **The inclusion of submitting data to CRANE as a requirement in the National Service Specification for cleft lip and/or palate services should continue to improve the quality and completeness of data held in the CRANE database.**

Based on the data reported to CRANE, we have highlighted some areas that should be addressed by maternity, paediatric, psychological, cleft and dental services to improve care and outcomes.

### Diagnosis, Referral and Contact

1. Antenatal diagnosis rates of cleft lip, with or without cleft palate, are still falling below the NHS Fetal Anomaly Screening Programme target detection rate of 75%<sup>80</sup>.

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<sup>78</sup> 679,106 Births in England and Wales and 23,076 Births in Northern Ireland in 2017 (Office for National Statistics, <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/datasets/birthsummarytables> // Northern Ireland Statistics and Research Agency, <http://www.nisra.gov.uk/demography/default.asp8.htm>)

<sup>79</sup> See Report number 1. 'Outcomes' behind the CRANE Database log-in for further detail- <https://www.crane-database.org.uk/>

<sup>80</sup> Donna Kirwan and NHS Fetal Anomaly Screening Programme in collaboration with the Royal College of Obstetricians and Gynaecologists (RCOG), British Maternal and Fetal Medicine Society (BMFMS) and the Society and College of Radiographers (SCoR), NHS Fetal Anomaly Screening Programme. 18+0 to 20+6 Weeks Fetal Anomaly Scan National Standards and Guidance for England, 2010, NHS Fetal Anomaly Screening Programme: Exeter.

2. Almost one third of children with a cleft palate alone (30%) are being diagnosed late according to the national standard, whereby clefts should be diagnosed within 24 hours of birth to enable immediate referral to a specialist hospital<sup>81</sup>.
3. Eighty-three percent of the children born in 2017 with a cleft were referred by a maternity unit to a Cleft Unit within 24 hours of birth. This proportion varied according to cleft type (although not significantly) and according to the unit receiving the referrals (significantly).
4. Units established contact with 96% of parents within 24 hours of their child's referral. This proportion varied according to cleft type (although not significantly) and according to the unit establishing contact (significantly). Despite this statistically significant variation between units, overall rates of contact within 24 hours remain high (as for previous reporting years). This demonstrates the commitment of units to ensure timely response to new referrals of babies born with a cleft, to help support these babies and their families in the important initial stages.
5. Despite these positive figures reported for the two points above, the proportion of children missing data for both referral time and first contact time could still be improved. In addition, prompt referral continues to be recommended to ensure that the baby and their family receive appropriate care and support as soon as possible.

### Cleft-related outcomes at five years

6. Children with a cleft are at increased risk of poor oral health. Children with a cleft affecting both the lip and palate are at the greatest risk of caries and may benefit from targeted preventive intervention. Nevertheless, average treatment and care indices (of 76% and 68% respectively) across units indicate that, in the majority of cases, units have mechanisms in place to deal with any dental disease occurring.
7. Approximately one quarter of children with a complete UCLP have poor dental arch relationships (26%) that may benefit from further surgery to correct facial disproportion. While there is room for improvement, this proportion is substantially lower than the 36% of five-year-old children with a cleft who were reported by CSAG to have poor dental arch relationships in 1996<sup>82</sup>.
8. Close to three quarters of children (61%) with a complete speech assessment had speech scores that would suggest their speech is not significantly different from their non-cleft peer group, with scores suggesting they have achieved *speech within the normal range*. This means that the national speech outcome standard #1 target of 55%<sup>83</sup> was not only met, but it was exceeded (on average) by the CRANE cohort born in 2007-2010.

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<sup>81</sup> Bannister P. Management of infants born with a cleft lip and palate. Part 1. *Infant*, 2008. 4(1): p. 5-8.

<sup>82</sup> Clinical Standards Advisory Group, Clinical Standards Advisory Group. Report of a CSAG Committee on cleft lip and/or palate, 1998, The Stationery Office, London.

<sup>83</sup> Based on the national outcome mean resulting from statistical analysis on 2004-06 Speech Outcome data – completed by the Lead Speech and Language Therapy Group, with statistical support from the Cleft Collective in Manchester, and presented in April 2014 to the Leads group.

9. The psychology data suggests that a higher proportion of children born with a cleft have a Strengths and Difficulties Questionnaire (SDQ) Total score in the high and very high ranges than is reported in the population norms. For the majority of these children and families, the team psychologist identified psychological concerns and provided psychological input. An additional 21% of children with lower scores on the SDQ had psychological concerns identified, highlighting the importance of a face-to-face psychosocial screen and discussion.

#### **Hospital outpatient appointments at seven years of age in England**

10. National hospital outpatient data in England have revealed that cleft type is not the only determining factor in the number or type of appointments attended by children with a non-syndromic cleft around the age of seven years. Substantial regional differences exist in outpatient service provision for these children. Differences in appointment volume and appointment specialty type were apparent and the burden of care for relevant cleft specialties varied considerably between the 13 cleft Units in England.

# Appendices

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## Appendix 1: CRANE Project Team

### Members of CRANE Project Team

Scott Deacon	Clinical Project Lead / Lead Consultant Orthodontist	Clinical Effectiveness Unit / South West Cleft Unit, University Hospital Bristol NHS Foundation Trust University of Bristol
Jibby Medina	Research Fellow	Clinical Effectiveness Unit
Kate Fitzsimons	Research Fellow	Clinical Effectiveness Unit
Jan van der Meulen	Clinical Epidemiologist	Clinical Effectiveness Unit / London School of Hygiene and Tropical Medicine
Catherine Foster	CEU Research Coordinator (From December 2017)	Clinical Effectiveness Unit
Min Hae Park	Assistant Professor (From June 2018)	Clinical Effectiveness Unit
Lynn Copley	Data Manager (Up until April 2018)	Clinical Effectiveness Unit

## Appendix 2: Governance and funding

### Ownership

It has been agreed that the “ownership” of the CRANE Database lies with the Craniofacial Society of Great Britain and Ireland (CFSGBI) as it represents the multidisciplinary group of professionals involved in the care of patients with a cleft lip and/or palate.

### Cleft Development Group

The Cleft Development Group is a body with two distinct roles. Firstly, it is responsible for making arrangements for the running and commissioning of the CRANE Database.

Secondly, it is responsible for providing guidance on all aspects of the delivery of cleft care in England and Wales. It includes representatives from all the stakeholders in cleft care in England and Wales, including commissioners, public health consultants/regional cleft leads, specialists in the provision of cleft care, and parents and patients. It also has representatives from the health services in Wales, Scotland and Northern Ireland, as well as a representative from the Republic of Ireland cleft service.

[The Cleft Development Group](#) CRANE web page provides detail on the CDG Membership and Terms of Reference.

### Funding

Funding of the CRANE Database is currently coordinated and agreed by representatives of the national Specialised Commissioning Group for England, the Wales Specialised Health Services Committee, and the Northern Ireland Specialist Services Commissioning Team. Funds are raised through a levy calculated on a weighted per capita basis from the commissioning bodies in England, Wales and Northern Ireland. The levy is currently collected by Specialised Commissioning (East Midlands).

### Appendix 3: Regional Cleft Centres and Managed Clinical Network and their associated regions / units

The CRANE Database covers England, Wales and Northern Ireland. Cleft care is currently delivered by eight Regional Cleft Centres and two Managed Clinical Networks. Several of the Regional Cleft Centres are split between two hospitals, where the primary surgery is usually undertaken, and therefore Hospitals/ Administrative Units in a region may submit data separately to the CRANE Database , as shown in the Table below.

<b>Regional Cleft Centre / MCN</b>	<b>Administrative Unit</b>
Northern & Yorkshire	Royal Victoria Infirmary, Newcastle Leeds General Infirmary, Leeds
North West & North Wales & Isle of Man	Alder Hey Children’s Hospital, Liverpool Royal Manchester Children’s Hospital, Manchester
Trent	Nottingham City Hospital, Nottingham
West Midlands	Birmingham Children’s Hospital, Birmingham
East	Addenbrooke’s Hospital, Cambridge
North Thames*	Great Ormond Street Hospital (GOSH), London Broomfield Hospital, Chelmsford
The Spires**	John Radcliffe Hospital, Oxford & Salisbury District Hospital, Salisbury
South Wales & South West	Morrison Hospital, Swansea University Hospitals Bristol***
South Thames	Guy's and St Thomas’ Trust (GSTT), London
Northern Ireland	Royal Belfast Hospital for Sick Children, Belfast

Notes:

MCN – Managed Clinical Network.

\*Data for GOSH and Broomfield units combined upon request by the Spires’ Clinical Director (January 2017).

\*\*Data for Oxford and Salisbury units combined upon request by the Spires’ Clinical Director (June 2016).

\*\*\*Frenchay Hospital, Bristol service moved to University Hospitals Bristol during 2014.

## Appendix 4: Diagnosis and Procedure Codes, Hospital Episode Statistics (HES)

International classification of Disease 10th Revision (ICD-10) diagnostic codes for cleft lip and/or palate.

Code	Description
Q35	Cleft palate
Q36	Cleft lip
Q37	Cleft palate with cleft lip

Classification of Surgical Operations and Procedures 4th Revision (OPCS-4) codes for cleft lip and cleft palate repairs.

Code	Description
F031	Correction of deformity to lip
F291	Correction of deformity to palate

International classification of Disease 10th Revision (ICD-10) diagnostic codes for syndromes and anomalies used to identify 'syndromic' cleft patients. Patients were defined as 'syndromic' if there was a record of any of the following codes in any of the fourteen diagnosis code fields for any of that patient's HES episodes.

Code	Description
D821	Di George's syndrome
<b>Congenital malformations of the nervous system (Q00-Q07)</b>	
Q00	Anencephaly and similar malformations
Q01	Encephalocele
Q02	Microcephaly
Q03	Congenital hydrocephalus
Q04	Other congenital malformations of brain
Q05	Spina bifida
Q06	Other congenital malformations of spinal cord
Q07	Other congenital malformations of nervous system
Q16	Congenital malformations of ear causing impairment of hearing
Q18	Other congenital malformations of face and neck
<b>Congenital malformations of the circulatory system (Q20-Q28)</b>	
Q20	Congenital malformations of cardiac chambers and connections
Q21	Congenital malformations of cardiac septa
Q22	Congenital malformations of pulmonary and tricuspid valves
Q23	Congenital malformations of aortic and mitral valves
Q24	Other congenital malformations of heart
Q25	Congenital malformations of great arteries
Q26	Congenital malformations of great veins
Q27	Other congenital malformations of peripheral vascular system
Q28	Other congenital malformations of circulatory system
Q380	Congenital malformations of lips, not elsewhere classified
Q75	Other congenital malformations of skull and face bones
Q86	Congenital malformation syndromes due to known exogenous causes, not elsewhere classified
Q87	Other specified congenital malformation syndromes affecting multiple systems

*Continued on next page...*



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Code	Description
	<b>Chromosomal abnormalities, not elsewhere classified (Q90-99)</b>
Q90	Down's syndrome
Q91	Edwards' syndrome and Patau's syndrome
Q92	Other trisomies and partial trisomies of the autosomes, not elsewhere classified
Q93	Monosomies and deletions from the autosomes, not elsewhere classified
Q95	Balanced rearrangements and structural markers, not elsewhere classified
Q96	Turner's syndrome
Q97	Other sex chromosome abnormalities, female phenotype, not elsewhere classified
Q98	Other sex chromosome abnormalities, male phenotype, not elsewhere classified
Q99	Other chromosome abnormalities, not elsewhere classified

## Appendix 5: Five Year Old Index scores detail

Number (%) of CRANE-registered consented children born between 2004 and 2011 with a complete unilateral cleft lip and palate, according to Five Year Old Index scores and region / unit.

Regional centre / MCN	Administrative Unit	Five Year Old Index*					All <sup>a</sup>
		n (%)					
		1	2	3	4	5	
Northern & Yorkshire	Newcastle	8 (14.5)	7 (12.7)	23 (41.8)	11 (20)	6 (10.9)	55
	Leeds	8 (11.8)	27 (39.7)	20 (29.4)	12 (17.6)	1 (1.5)	68
North West & North Wales	Liverpool	4 (6.5)	18 (29)	20 (32.3)	14 (22.6)	6 (9.7)	62
	Manchester	3 (4.5)	26 (38.8)	18 (26.9)	11 (16.4)	9 (13.4)	67
Trent	Nottingham	5 (7.5)	24 (35.8)	24 (35.8)	7 (10.4)	7 (10.4)	67
West Midlands	Birmingham	9 (8.1)	36 (32.4)	37 (33.3)	22 (19.8)	7 (6.3)	111
East	Cambridge	4 (6.2)	22 (33.8)	21 (32.3)	15 (23.1)	3 (4.6)	65
North Thames	GOSH & Chelms.	6 (8.5)	30 (42.3)	24 (33.8)	11 (15.5)	0 (0)	71
The Spire	Oxford & Salisbury	11 (9)	42 (34.4)	37 (30.3)	25 (20.5)	7 (5.7)	122
South Wales & South West	Swansea	0 (0)	2 (18.2)	5 (45.5)	2 (18.2)	2 (18.2)	11
	Bristol	1 (2.3)	16 (37.2)	10 (23.3)	10 (23.3)	6 (14)	43
South Thames	Guy's and St Thomas'	10 (8.3)	46 (38.3)	36 (30)	18 (15)	10 (8.3)	120
Northern Ireland	Belfast	1 (5.3)	4 (21.1)	9 (47.4)	3 (15.8)	2 (10.5)	19
All	All	70 (7.9)	300 (34.1)	284 (32.2)	161 (18.3)	66 (7.5)	881

\* Exclusions from 'All' values (not mutually exclusive): Children with an incomplete UCLP, with submucous cleft palates<sup>84</sup>, children who died before the age of five, and 371/1,252 (29.6%) children missing Five Year Old Index scores data.

<sup>84</sup> Submucous cleft palate patients excluded from all five year outcomes as all/most teams do not audit these patients.

## Appendix 6: Cleft Audit Protocol for Speech: Ratings for individual 16 CAPS-A parameters

### Resonance and Nasal Airflow

In Table A, ratings are colour-coded as green when the child's palate is functioning well in terms of the assessed parameter. No action, either speech therapy or surgery, would be required with green ratings. Amber for hyponasality is indicative of nasal obstruction, while amber or red for hypernasality, nasal emission or nasal turbulence are indicative of structurally-related speech difficulties that may involve palate function and/or palatal fistulae. These difficulties may require surgical treatment.

**Table A.** Number (%) of CRANE-registered <sup>a</sup> consented children born with a cleft palate in 2009-2011, according to the four parameters for resonance and nasal airflow

	Description	Score	N	(%)
RESONANCE – HYPERNASALITY				
	Absent	0	1,019	(77.9)
	Borderline – minimal	1	143	(10.9)
	Mild – evident on close vowels	2	77	(5.9)
	Moderate – evident on open and close vowels	3	36	(2.8)
	Severe – evident on vowels and voiced consonants	4	33	(2.5)
RESONANCE – HYPONASALITY				
	Absent	0	1,089	(83.3)
	Mild – partial dentalization of nasal consonants and adjacent vowels	1	204	(15.6)
	Marked – dentalization of nasal consonants and adjacent vowels	2	15	(1.1)
NASAL AIRFLOW – AUDIBLE NASAL EMISSION				
	Absent on pressure consonants	0	1,195	(91.4)
	Occasional: pressure consonants affected <10% of the sample	1	82	(6.3)
	Frequent: pressure consonants affected >10% of the sample	2	31	(2.4)
NASAL AIRFLOW – NASAL TURBULENCE				
	Absent on pressure consonants	0	1,031	(78.8)
	Occasional: pressure consonants affected <10% of the sample	1	245	(18.7)
	Frequent: pressure consonants affected >10% of the sample	2	32	(2.4)
<b>TOTAL</b>			<b>1,308</b>	<b>(100)</b>

<sup>a</sup> Registered in CRANE by 11 July 2018.

### Cleft Speech Characteristics (CSCs)

Table B presents the cleft speech characteristics (CSCs). A colour coding of green indicates the CSC is absent or considered to be a minor speech characteristic unlikely to require intervention. A colour coding of amber or red indicates the CSC is affecting one or more consonants to the extent that therapy and / or surgery may be required.

**Table B.** Number (%) of CRANE-registered<sup>a</sup> consented children born with a cleft palate in 2009-2011, according to the twelve Cleft Speech Characteristics (CSCs) parameters.

Cleft Speech Characteristics (CSCs)		Score	N (%)
ANTERIOR ORAL CSCs	1. Dentalisation / Interdentalisation	A	1,038 (79.4)
		B	270 (20.6)
	2. Lateralisation / Lateral	A	1,210 (92.5)
		B	55 (4.2)
		C	43 (3.3)
	3 Palatalisation / Palatal	A	1,002 (76.6)
B		150 (11.5)	
C		156 (11.9)	
POSTERIOR ORAL CSCs	4. Double Articulation	A	1,266 (96.8)
		B	37 (2.8)
		C	5 (0.4)
	5. Backed to Velar / Uvular	A	1,137 (86.9)
		C	74 (5.7)
		D	97 (7.4)
NON ORAL CSCs	6. Pharyngeal Articulation	A	1,284 (98.2)
		C	10 (0.8)
		D	14 (1.1)
	7. Glottal Articulation	A	1,226 (93.7)
		C	42 (3.2)
		D	40 (3.1)
	8. Active Nasal Fricatives	A	1,179 (90.1)
		C	80 (6.1)
		D	49 (3.7)
9. Double Articulation	A	1,282 (98)	
	C	17 (1.3)	
	D	9 (0.7)	
PASSIVE CSCs	10. Weak and or nasalised consonants	A	1,231 (94.1)
		C	30 (2.3)
		D	47 (3.6)
	11. Nasal realisation of plosives	A	1,274 (97.4)
		C	16 (1.2)
		D	18 (1.4)
12. Gliding of fricatives	A	1,285 (98.2)	
	C	14 (1.1)	
	D	9 (0.7)	
<b>TOTAL</b>			<b>1,308 (100)</b>

<sup>a</sup> Registered in CRANE by 11 July 2018.

## Appendix 7: Cleft Audit Protocol for Speech: Speech Outcome Standards

Number (%) of CRANE-registered consented children born in 2009 - 2011 with reported speech outcomes at five years of age, meeting each speech outcome standard, according to Regional Centre / Administrative Unit.

Regional Centre	Admin Unit	Reported **	n	Standard 1		Standard 2a		Standard 3			
				Theo. Stnd: 50%+ (%)	Nat Outc Mean 2004-06:	Theo. Stnd: 70%+ (%)	Nat Outc Mean 2004-06:	Theo. Stnd: 50%+ (%)	Nat Outc Mean 2004-06:		
Northern & Yorkshire	Newcastle	76	40	53	53	41	54	54	46	61	61
	Leeds	87	42	48	48	50	57	57	55	63	63
N West & North Wales	Liverpool	78	50	64	64	54	69	69	57	73	73
	Manchester	113	74	65	65	76	67	67	81	72	72
Trent	Nottingham	126	72	57	57	97	77	77	81	64	64
W Midlands	Birmingham	156	95	61	61	126	81	81	103	66	66
	East Cambridge	66	47	71	71	49	74	74	50	76	76
N Thames	GOS & Chel	155	98	63	63	114	74	74	112	72	72
The Spires	Oxf & Salisb	127	80	63	63	98	77	77	88	69	69
S Wales & South West	Swansea	77	52	68	68	64	83	83	55	71	71
	Bristol	76	43	57	57	59	78	78	49	64	64
S Thames	GSTT	119	68	57	57	74	62	62	74	62	62
North Ireland	Belfast	52	39	75	75	43	83	83	41	79	79
<b>All</b>	<b>All</b>	<b>1,308</b>	<b>800</b>	<b>61</b>	<b>61</b>	<b>945</b>	<b>72</b>	<b>72</b>	<b>892</b>	<b>68</b>	<b>68</b>

\*\* Exclusions (not mutually exclusive): children who died before the age of five years, with submucous cleft palates, missing one or more of all 16 CAPS-A data items, born with either a CL or a non-specified cleft type, and syndromic children.

## Appendix 8: Psychology screening scores detail

### Data completeness

Number (%) of CRANE-registered consented children born with a cleft lip or palate (2011), with psychology outcome data or reasons this outcome was not collected at five years of age, according to region / unit.

Regional centre / MCN	Administrative Unit	Psychology***							
		Eligible consented cases	Outcome collected: At least 1 of 9 items		Outcome not collected: reason provided		Total cases acc. for (%)	Missing Data	
			N	n	(%)	n		(%)	N
Northern & Yorkshire	Newcastle	49	37	75.5%	12	24.5%	100%	0	(0)
	Leeds	63	42	66.7%	21	33.3%	100%	0	(0)
North West & North Wales	Liverpool	50	39	78%	9	18%	96%	2	(4)
	Manchester	68	33	48.5%	10	14.7%	63.2%	25	(36.8)
Trent	Nottingham	85	0	0%	33	38.8%	38.8%	52	(61.2)
West Midlands	Birmingham	97	92	94.8%	0	0%	94.8%	5	(5.2)
East	Cambridge	55	39	70.9%	15	27.3%	98.2%	1	(1.8)
North Thames	GOSH & Chelms.	123	106	86.2%	14	11.4%	97.6%	3	(2.4)
The Spires	Oxford & Salisbury	93	48	51.6%	6	6.5%	58.1%	39	(41.9)
South Wales & South West	Swansea	44	39	88.6%	2	4.5%	93.2%	3	(6.8)
	Bristol	51	27	52.9%	11	21.6%	74.5%	13	(25.5)
South Thames	Guy's and St Thomas'	82	67	81.7%	15	18.3%	100%	0	(0)
Northern Ireland	Belfast	38	17	44.7%	11	28.9%	73.7%	10	(26.3)
<b>All</b>	<b>All</b>	<b>898</b>	<b>586</b>	<b>65.3%</b>	<b>159</b>	<b>17.7%</b>	<b>83%</b>	<b>153</b>	<b>17%</b>

\*\*\* Eligibility exclusions (not mutually exclusive): (Consent), children who died before the age of five years, with submucous cleft palates, and syndromic children.

### Relationship between TIM and SDQ scores

Number (%) of CRANE-registered consented children born with a cleft lip or palate (2011), within each of the Tiers of Involvement Measure (TIM) levels according to SDQ Total difficulties bands.

SDQ	TIM								
	0	1a	1b	2a	2b	2c	3	4.	All
Close to aver.	13 (4.1)	186 (58.5)	4 (1.3)	54 (17)	21 (6.6)	22 (6.9)	14 (4.4)	4 (1.3)	<b>318 (100)</b>
Slightly raised	0 (0)	12 (37.5)	3 (9.4)	2 (6.3)	6 (18.8)	3 (9.4)	1 (3.1)	5 (15.6)	<b>32 (100)</b>
High	2 (7.7)	8 (30.8)	1 (3.8)	3 (11.5)	3 (11.5)	4 (15.4)	2 (7.7)	3 (11.5)	<b>26 (100)</b>
Very high	0 (0)	6 (18.2)	5 (15.2)	2 (6.1)	3 (9.1)	7 (21.2)	4 (12.1)	6 (18.2)	<b>33 (100)</b>
<b>All</b>	<b>15 (3.7)</b>	<b>212 (51.8)</b>	<b>13 (3.2)</b>	<b>61 (14.9)</b>	<b>33 (8.1)</b>	<b>36 (8.8)</b>	<b>21 (5.1)</b>	<b>18 (4.4)</b>	<b>409 (100)</b>

Eligibility exclusions (not mutually exclusive): (Consent), children who died before the age of five years, with submucous cleft palates, and syndromic children.

## Appendix 9: Outpatient hospital appointments: Tables of data for figures in Chapter 4

Table of data for Figure 8. Percentage of children with a non-syndromic cleft according to cleft type and how many hospital outpatient appointments they attended during school Year 2.

Cleft type	N	% of children according to total number of appointments during school Year 2				
		0	1	2-5	6-10	>10
CL	909	54.2	20.9	19.8	4.1	1.0
CP	1230	33.6	18.9	38.3	7.8	1.4
UCLP	957	21.4	21.6	45.0	9.2	2.7
BCLP	370	15.4	19.7	42.2	17.8	2.7
All	3466	33.7	20.3	37.7	8.3	2.0

**Notes:** 61 children do not have a specified cleft type, hence the total number is not equal to the sum of the four cleft type groups. CL, cleft lip; CP, cleft palate; UCLP, unilateral cleft lip and palate; BCLP, bilateral cleft lip and palate

Table of data for Figure 9. Percentage of children with a non-syndromic cleft according to cleft type and the specialties seen in hospital outpatient appointments during school Year 2.

Cleft type	N	% of children with appointments under each specialty during school Year 2						Other / non-cleft
		ENT / Audiology	Cleft-related surgery	Dental	Paediatrics	SLT	Ophthalmology	
CL	909	7.3	16.9	20.2	7.9	0.2	6.6	9.6
CP	1230	39.5	23.8	13.1	16.2	4.1	9.6	12.8
UCLP	957	41.8	36.2	35.1	13.2	4.8	8.6	12.5
BCLP	370	43.0	44.3	44.6	17.6	8.1	12.7	14.9
All	3466	32.1	27.6	24.4	13.3	3.7	8.9	12.1

**Notes:** 61 children do not have a specified cleft type, hence the total number is not equal to the sum of the four cleft type groups. CL, cleft lip; CP, cleft palate; UCLP, unilateral cleft lip and palate; BCLP, bilateral cleft lip and palate; ENT, ear, nose and throat; SLT, speech and language therapy

Table of data for Figure 10. Proportion of all hospital appointments attended by non-syndromic children during school year 2, according to cleft type and the various treating specialties.

Cleft type	N	% of all appointments made up by each specialty						Other / non-cleft
		ENT / Audiology	Cleft-related surgery	Dental	Paediatrics	SLT	Ophthalmology	
CL	1113	12.0	17.9	26.7	16.1	0.6	13.3	16.4
CP	2609	37.5	15.3	8.6	13.6	3.5	11.4	12.7
UCLP	2575	30.7	19.5	20.9	9.1	5.1	7.4	10.3
BCLP	1344	24.0	20.5	22.8	8.3	8.6	10.1	8.4
All	7641	29.1	18.0	17.9	11.5	4.5	10.1	11.7

**Notes:** \* 2.75% appointments have more than one specialty recorded, hence totals are >100%; CL, cleft lip; CP, cleft palate; UCLP, unilateral cleft lip and palate; BCLP, bilateral cleft lip and palate; ENT, ear, nose and throat; SLT, speech and language therapy

Table of data for Figure 12. Percentage of children with a non-syndromic cleft according to cleft Unit and how many hospital outpatient appointments they attended during school Year 2.

Administrative Unit	N	% of children according to total number of appointments during school Year 2				
		0	1	2-5	6-10	>10
Newcastle	292	26.0	17.8	42.5	12.0	1.7
Leeds	321	39.9	21.8	31.8	5.0	1.6
Liverpool	192	31.8	19.8	40.1	5.7	2.6
Manchester	290	41.0	21.7	31.4	4.8	1.0
Nottingham	379	27.2	22.2	38.3	10.8	1.6
Birmingham	504	41.1	13.9	33.3	10.1	1.6
Cambridge	266	32.7	28.6	30.5	6.0	2.3
GOSH	142	36.6	17.6	37.3	7.0	1.4
Chelmsford	153	37.9	18.3	32.7	9.2	2.0
Oxford	174	31.0	23.0	39.1	5.8	1.2
Salisbury	221	42.1	18.6	27.2	9.5	2.7
Bristol	283	22.3	21.9	42.4	8.1	5.3
Guy's	310	28.7	21.9	38.7	9.0	1.6
<b>All</b>	<b>3527</b>	<b>33.7</b>	<b>20.3</b>	<b>35.7</b>	<b>8.2</b>	<b>2.0</b>

**Notes:** CL, cleft lip; CP, cleft palate; UCLP, unilateral cleft lip and palate; BCLP, bilateral cleft lip and palate

Table of data for Figures 14-16 Percentage of children with a non-syndromic cleft seeing each specialty in hospital outpatient appointments during school Year 2, according to cleft Unit

Administrative Unit	N	% of children with appointments under each specialty during school Year 2						Other / non-cleft
		ENT / Audiology	Cleft-related surgery	Dental	Paediatrics	SLT	Ophthalmology	
Newcastle	292	50.34	40.41	16.44	10.62	0.68	12.33	11.99
Leeds	321	33.33	5.61	19.94	15.26	0.93	9.03	11.84
Liverpool	192	26.56	36.98	19.79	18.23	0.00	9.38	7.29
Manchester	290	20.00	29.31	11.38	14.83	0.34	5.17	10.34
Nottingham	379	35.36	20.84	39.84	17.41	0.26	8.18	9.76
Birmingham	504	31.75	28.77	13.29	10.12	8.53	9.72	14.29
Cambridge	266	22.93	29.70	32.71	14.29	3.38	7.14	10.15
GOSH	142	30.99	38.03	24.65	11.97	6.34	6.34	9.86
Chelmsford	153	31.37	34.64	12.42	13.07	8.50	9.15	16.34
Oxford	174	36.78	24.71	13.22	8.62	2.87	9.77	15.52
Salisbury	221	27.60	8.14	25.79	11.31	11.76	7.24	17.65
Bristol	283	36.40	29.33	47.35	11.66	5.30	12.01	13.78
Guy's	310	30.32	41.29	32.26	16.13	0.65	7.10	9.03
<b>All</b>	<b>3527</b>	<b>32.10</b>	<b>27.62</b>	<b>24.27</b>	<b>13.41</b>	<b>3.66</b>	<b>8.76</b>	<b>12.05</b>

**Notes:** 61 children do not have a specified cleft type, hence the total number is not equal to the sum of the four cleft type groups. CL, cleft lip; CP, cleft palate; UCLP, unilateral cleft lip and palate; BCLP, bilateral cleft lip and palate; ENT, ear, nose and throat; SLT, speech and language therapy

Table of data for Figure 17 Proportion of all hospital appointments attended by non-syndromic children during school Year 2, according to cleft Unit and the various treating specialties\*

Administrative Unit	N	% of all appointments made up by each specialty						
		ENT / Audiology	Cleft-related surgery	Dental	Paediatrics	SLT	Ophthalmology	Other / non-cleft
Newcastle	716	34.9	20.3	13.0	8.2	0.3	14.1	9.2
Leeds	598	35.6	3.7	14.7	19.1	1.3	15.6	11.5
Liverpool	414	24.6	19.8	17.2	16.7	0.0	14.0	10.1
Manchester	461	26.9	26.9	11.7	16.1	0.2	5.6	14.3
Nottingham	926	26.9	14.8	29.2	15.1	0.1	7.3	8.9
Birmingham	1093	35.8	17.2	9.7	7.9	6.7	12.0	14.4
Cambridge	517	20.3	20.5	22.6	13.4	8.2	8.5	11.0
GOSH	300	26.0	26.3	21.7	7.7	11.7	7.7	13.0
Chelmsford	326	28.8	21.5	9.2	9.5	11.4	8.0	13.8
Oxford	341	35.2	16.4	9.1	7.9	2.9	9.7	19.1
Salisbury	364	25.2	9.5	15.1	8.8	15.1	6.7	19.6
Bristol	890	23.5	17.2	25.2	10.0	7.1	11.0	10.0
Guy's	708	29.7	26.8	22.7	11.4	0.7	6.5	4.9
<b>All</b>	<b>7754</b>	<b>29.2</b>	<b>18.0</b>	<b>17.8</b>	<b>11.7</b>	<b>4.5</b>	<b>10.0</b>	<b>11.7</b>

**Notes:** \* 2.75% appointments have more than one specialty recorded, hence totals are >100%; CL, cleft lip; CP, cleft palate; UCLP, unilateral cleft lip and palate; BCLP, bilateral cleft lip and palate; ENT, ear, nose and throat; SLT, speech and language therapy