**Title:** Longitudinal educational attainment among children with isolated oral cleft: a cohort study

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Word count: 2498 (excluding title page, abstract, tables, figures and references) Acknowledgements: HES data were made available by NHS Digital; NPD data were made available by the Department for Education. The CRANE database was funded by the National Specialised Commissioning Group for England and the Wales Specialised Health Services Committee, and is overseen by the UKNHS Cleft Development Group. The funders did not have a role in in study design; in the collection, analysis, and interpretation of data; in the writing of the report; and in the decision to submit the paper for publication Funding: This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

**Contributorship statement:** MHP conceptualised and designed the study, carried out the analyses and interpretation of data, drafted the initial manuscript and revised and finalised

the manuscript for submission. KJF acquired and processed the data, interpreted the data and edited the manuscript. SD interpreted the data, contributed clinical aspects and edited the manuscript. JM acquired and processed the data, and edited the manuscript. MAHW acquired and processed the data, and edited the manuscript. SB interpreted the data, contributed clinical aspects and edited the manuscript. CJHR interpreted the data, contributed clinical aspects and edited the manuscript. JvdM conceptualised the study, interpreted the data and edited the manuscript. All authors read and approved the final manuscript.

Key words: orofacial cleft; cleft lip; cleft palate; educational outcomes

### Abstract

**Objectives:** 1) To explore differences in educational attainment between children born with isolated clefts and the general population at ages 5, 7 and 11 years; 2) To describe longitudinal changes in attainment among children with cleft through primary education. **Design:** Analysis of Cleft Registry and Audit Network data linked to national educational outcomes

Setting: English state schools

Patients: 832 children born with isolated cleft, aged 5 in 2006-2008

**Main outcome measures:** Difference in teacher-assessed attainment between children with a cleft and general population at each age, for all children and by cleft type. Percentage of children with low attainment at age 5 who had low attainment at age 11, for all children and by cleft type.

**Results:** Children with a cleft had lower attainment than the general population in all subject areas [Z-score range: -0.29 (95%CI -0.36 to -0.22) to -0.22 (95%CI -0.29 to -0.14)]. This difference remained consistent in size at all ages, and was larger among children with a cleft affecting the palate (cleft palate/cleft lip and palate, CP/CLP) than those with a cleft lip (CL). Of 216 children with low attainment in any subject at age 5, 54.2% had low attainment in at least one subject at age 11. Compared to children with CL, those with CP/CLP were more likely to have persistent low attainment.

**Conclusions:** An educational attainment gap for children born with isolated clefts is evident throughout primary education. Almost half of children with low attainment at age 5 achieve normal attainment at age 11.

### **Key messages**

What is already known on this topic: Children born with isolated clefts have lower academic attainment than the general population, but it is unclear how this population attainment gap or individual educational outcomes change with age.

What this study adds: A population educational attainment gap for children with isolated clefts is evident throughout primary education, and is largest among children with a cleft affecting the palate. Almost half of children with low attainment at age 5 progress to achieve attainment within the normal range at age 11.

How this study might affect research, practice or policy: Longer-term research is needed to determine whether the attainment gap persists into adolescence and adulthood, and to identify effective educational interventions for groups of children at risk of persistent low attainment.

### Introduction

In England, around 900 children are born with an oral cleft (cleft lip and/or cleft palate) each year.<sup>1</sup> Several cross-sectional studies have shown that children and adolescents with clefts are at increased risk of learning difficulties,<sup>2, 3</sup> and have lower levels of achievement at school than their unaffected peers.<sup>2, 4-7</sup> Social and emotional challenges associated with cleft can influence children's educational experiences and outcomes.<sup>8-10</sup> A population-based study of 2,802 children born with an isolated (non-syndromic) oral cleft in England 2001- 2007,<sup>7</sup> identified that children with clefts had lower educational attainment than the general population across all areas of learning at age 5 years. This difference was larger among children with cleft palates than those with cleft lip only. Similarly in adolescence, a study of 1,992 Swedish students found that those born with an oral cleft between 1973 and 1986 had increased odds of not receiving their school leaving certificate at age 16, and were more likely to receive lower grades than students in the general population.<sup>5</sup>

Just one US study has examined longitudinal attainment in children with oral clefts, identifying academic trajectories from grades 2 to 11 in 586 children with isolated clefts.<sup>11</sup> This study found that children with clefts were more likely to have persistent low achievement in school than their unaffected classmates. However, this study included children born over a 20-year period (1983-2003), and is unlikely to be representative of those who have received cleft care in recent decades when notable improvements in quality of care and outcomes have taken place.<sup>12, 13</sup>

The aims of this study were to explore differences in educational attainment between children born with isolated clefts and the general population (the 'attainment gap') at ages 5, 7 and 11 years, and to describe longitudinal changes in attainment among children with clefts through primary education.

# Methods

# Study cohort and data linkage

The study cohort was identified from the Cleft Registry and Audit Network (CRANE) database, which collects information on all children born with an oral cleft in England, Wales and Northern Ireland. There were 2,301 children born in England who were aged 5 between 1 September 2006 and 31 August 2008, whose parents had given consent for their information to be included in CRANE. Of these, 2,122 (92.2%) had a linked record in the Hospital Episode Statistics (HES) database, which contained records on all admissions to English National Health Service (NHS) hospitals up to 31 March 2015. Linkage to HES was used to exclude 500 children identified as having additional anomalies or syndromes that may influence educational outcomes, based on the presence of specified International Statistical Classification of Diseases and Related Health Problems 10<sup>th</sup> Revision (ICD-10) diagnostic codes (Supplementary Material 1) in any diagnosis field of their HES records. Children with missing information on cleft type in CRANE (n=44) were excluded.

Data from 1,532 of the 1,578 children with an isolated cleft and known cleft type (97.1%) were linked to records in the National Pupil Database (NPD), a database of educational outcomes for all children attending state schools in England. The NPD provided information on teacher-assessed educational attainment at Early Years Foundation Stage (EYFS, age 5 years), Key Stage 1 (KS1, 7 years) and Key Stage 2 (KS2, 11 years). A cohort of 832 children with isolated clefts and who had educational data at ages 5, 7 and 11 years formed the study sample, representing two academic year cohorts (EYFS in 2006/07 and 2007/08).

### Educational outcomes

We analysed teacher-assessed attainment in three subject areas: English ( 'communication, language and literacy' at age 5, reading and writing at ages 7 and 11), Maths, and Science ('knowledge and understanding of the world' at age 5). At each stage, teachers assessed pupils' attainment against national expected levels of knowledge, skills and understanding in each subject. Attainment was assessed using a scale from 0 to 9 points at age 5, and levels (<1 to 6) at ages 7 and 11. Attainment levels at ages 7 and 11 were converted to point scores using conversions specified by the Department for Education,<sup>14</sup> to enable comparison across stages (Supplementary Material 2).

Low attainment was defined as being in the bottom 10% of the national distribution for attainment in any subject (Z-score <-1.28). The Z-score cut-offs that identified the bottom decile of the distributions for each subject were used to define low attainment at each age. A distribution-based approach using Z-scores was used to define low attainment because the proportions of children achieving expected levels of attainment varied across assessment stages and subjects.

#### Other variables

Information on sociodemographic characteristics was obtained from NPD records. The Income Deprivation Affecting Children Index (IDACI) is a measure of socioeconomic deprivation based on residential postcodes calculated as the proportion of children aged <16 living in low-income households in each small area of England. IDACI scores at age 5 were assigned to quintiles of the national ranking of scores. Eligibility for free school meals was also obtained as an indicator of deprivation. Children's ethnic group, categorised as 1) White or 2) Black, Asian and other non-white minority ethnic group (BAME), and special educational needs were also derived from NPD.

# Statistical analysis

To assess the size of the attainment gap, attainment in the study cohort was compared to results for the national population derived from published information for the relevant academic years (EYFS in 2006-2008). Differences in teacher-assessed attainment between children with a cleft and the general population at each age were summarised as Z-scores, calculated for each subject within each assessment year and by sex using published national data on attainment.<sup>15-17</sup> The calculated Z-scores represent the number of SDs by which observed scores differ from the national average (in the specified year and by sex), with a negative Z-score indicating a score below the national average and a positive score indicating a score above. Mean Z-scores and 95% confidence intervals (CI) are presented for each subject and age, and by cleft type (cleft lip – CL, cleft palate – CP, cleft lip and palate – CLP). To determine whether there was any change in the size of the attainment gap with age, mean Z-scores for each subject were compared across the three ages using repeated measures analysis of variance.

Longitudinal persistent low attainment was summarised as the percentage of children with low attainment in any subject at age 5 who had low attainment in at least one subject at age 11. The relationship between cleft type and persistent low attainment was further examined using multivariable logistic regression, adjusting for children's sociodemographic characteristics (sex, IDACI quintile, eligibility for free school meals, ethnicity, and cohort year). Sensitivity analyses including only IDACI quintile or eligibility for free school meals produced similar results to the model including both (Supplementary Material 3). Results are presented as odds ratios with 95% confidence intervals.

All statistical analyses were conducted using Stata V.17 (StataCorp, College Station, Texas, USA).

## Ethics

This study was exempt from NHS Health Research Authority ethics approval as it involves the analysis of an existing anonymised dataset that is collected and linked for the purpose of service evaluation.<sup>18</sup>

# Results

The characteristics of the 832 children included in the analysis are presented in Table 1. The cohort was typical of isolated cleft populations in England in terms of the distribution of cleft types and sex.<sup>7</sup> Over a quarter of children with isolated clefts were identified as having special educational needs at age 5 years, compared to 17% of all pupils across state schools.<sup>19</sup> Compared to the national distribution in England, children living in the most deprived areas were overrepresented in the cohort and those living in the least deprived areas were underrepresented. However, the proportion of children eligible for free school meals was similar to the national average for state primary schools in 2007.<sup>20</sup>

# Attainment gap between children with clefts and general population

Children with isolated oral clefts had attainment Z-scores that were lower than the national average in all three subject areas, ranging from -0.29 (95%CI -0.36 to -0.22) to -0.22

(95%CI -0.29 to -0.14) across all ages. Based on national distributions of attainment scores, a Z-score of 1 was equivalent to approximately 1.5 points at age 5, 4 points at age 7 and 5.5 points at age 11. The size of the attainment gap did not vary across assessment ages for any subject area (Figure 1).

The largest attainment gaps were consistently observed among children with CP, ranging from -0.43 (95%CI -0.57 to -0.30) for EYFS Science to -0.28 (95%CI -0.41 to -0.15) for KS1 Science (Figure 2). Among children with CL, the attainment gap was smaller across all subjects and attainment scores did not differ from the national average in KS2 English, EYFS and KS2 Maths, and EYFS Science.

## Longitudinal changes in individual attainment

Among the cohort of children with isolated oral clefts, 216 (26.0%) were categorised as having low attainment in any subject at age 5. Of these 216 children, 117 (54.2%) continued to have low attainment in at least one subject at age 11; the remaining 45.8% achieved "normal attainment" (not in bottom 10% of population) in all subject areas by age 11. Among the 616 children who had "normal attainment" in all subject areas at age 5, the majority (n=540, 87.7%) continued to have normal attainment at age 11, while 12.3% went on to have low attainment in at least one subject.

Persistent low attainment was associated with cleft type: compared to children with CL, those with CP and CLP were more likely to have persistent low attainment, even after adjusting for sociodemographic characteristics (adjusted OR for CP: 1.87, 95%Cl 1.06 to 3.27; adjusted OR for CLP 1.81, 95%Cl 1.03 to 3.16) (Table 2).

## Discussion

Children born with an isolated oral cleft in England have lower educational attainment than children in the general population at ages 5, 7 and 11 years, across all three assessed subject areas (English, Maths and Science). The size of the attainment gap observed at age 5 is similar at ages 7 and 11, and at the population level does not appear to narrow or broaden over the course of children's primary education. The largest attainment gaps were observed among children with CP and the smallest among those with CL. Among children identified as having low attainment at age 5, 46% go on to achieve attainment within the normal range in all subject areas at age 11. Children with a cleft affecting the palate are more likely to have persistent low attainment than those with CL.

As described previously, one other study has examined longitudinal academic achievement in a population-based cohort of children with isolated oral clefts.<sup>11</sup> Our study findings were consistent with this previous study, which found that children with oral clefts had lower attainment in reading, language and mathematics than their unaffected peers, and that academic achievement among children with clefts remained stable with age rather than narrowing in adolescence.

Genetic studies have indicated that those born with non-syndromic cleft are unlikely to have a genetic predisposition to low intelligence.<sup>21</sup> However, there are a number of factors associated with oral cleft that may impact on educational attainment. One such factor is the increased risk of hearing loss in early childhood.<sup>22</sup> Studies have shown that hearing loss is associated with poorer educational and cognitive outcomes.<sup>23, 24</sup> Children with CP are particularly affected by hearing loss (45.5% of children with CP are likely to receive grommets before age 5 years, compared to 4.5% of those with CL and 2.0% of children in the general population<sup>22</sup>), which could contribute to the poorer educational outcomes in this group. The psychosocial impacts of cleft, including social anxiety, isolation and teasing can also affect children's engagement at school, and impact on educational outcomes.<sup>8-10</sup>

Another factor that may affect attainment among children born with a cleft is neurotoxicity (damage to the brain or nervous system caused by exposure to toxic substances) from anaesthesia during cleft repair surgery, which typically takes place within the first year of life. Exposure to anaesthesia is of particular concern in infants, as there is evidence for critical periods of vulnerability for neurotoxicity in the developing brain.<sup>25</sup> Neurotoxicity is most likely to be an issue for those children who have undergone prolonged and/or repeated anaesthetic exposure, while those who have experienced brief exposure for a single procedure (e.g. for an uncomplicated lip repair surgery) may be less affected.<sup>25,</sup> <sup>26</sup>

Whilst there are factors that are likely to contribute to lower educational attainment among children with isolated clefts, the effects of some of these can be mitigated, e.g. the early identification and treatment of hearing loss.<sup>24</sup> Furthermore, the finding that almost half of children with low attainment at age 5 go on to achieve attainment within the normal range by the end of their primary education suggests that many children can progress with appropriate academic support. Further work exploring the influence of SEN provision and other types of educational support, such as speech and language therapy, may provide insights into effective interventions for children at risk of low attainment.

A strength of this study is the use of a large, population-based sample which is nationally representative of cleft populations in English state schools (~93% of all children in England).<sup>27, 28</sup> During the study period, case ascertainment in the cleft registry was estimated at around 95%, with high rates of parental consent for data linkage (97%).<sup>29</sup> The

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study demonstrates high levels of linkage to HES and NPD. Compared to previous studies, this study describes the attainment gap in a more contemporary cohort, which has benefitted from modern cleft care. A limitation of the study is the use of teacher-assessed educational attainment measures, which may be subject to bias. Although recent work indicates that UK teachers do not perceive the challenges associated with oral clefts to be a risk to long-term educational outcomes,<sup>30</sup> earlier studies suggested that teachers may have lower academic expectations of children with clefts.<sup>31</sup> From age 11 onwards, test-based attainment scores are available in the NPD. Longer-term follow-up using these more objective measures of attainment would provide evidence for the presence of an attainment gap and its potentially changing nature into adolescence. Another limitation of this study is the potential for misclassification of children with syndromic clefts, as identification of these children depends on the recording of diagnosed syndromes in HES. Furthermore, the list of ICD-10 codes used to identify children with isolated cleft only included those considered most likely to impact on the outcomes, and did not include all congenital malformations.<sup>32</sup>

# Conclusion

Children born with oral clefts have lower educational attainment than children in the general population in all subject areas throughout their primary education, and the size of the attainment gap is largest among children with a cleft palate. However, among children with a cleft who have low attainment at age 5, almost half go on to achieve attainment within the normal range at age 11. Further work is needed to determine whether the attainment gap persists longer term, and to identify effective interventions to support children at risk of low attainment.

	N (%)
N	832
Academic year cohort	
2006/07 <sup>1</sup>	428 (51.4%)
2007/08 <sup>2</sup>	404 (46.6%)
Sex	
Boys	466 (56.0%)
Girls	366 (44.0%)
Cleft type	
Cleft lip	232 (27.9%)
Cleft palate	301 (36.2%)
Unilateral cleft lip and palate	225 (27.0%)
Bilateral cleft lip and palate	74 (8.9%)
Ethnic group	
White	700 (84.1%)
BAME	132 (15.9%)
Deprivation quintile <sup>3</sup>	
1 (most deprived)	207 (25.3%)
2	177 (21.6%)
3	155 (19.0%)
4	133 (16.3%)
5 (least deprived)	146 (17.9%)
Eligible for free school meals at age 5	142 (17.2%)
Missing	7
Special educational needs at age 5	227 (27.5%)
Missing	7
Special educational needs at age 7	333 (40.0%)
Special educational needs at age 11	337 (40.5%)
Low attainment at age 5 <sup>4</sup>	216 (26.0%)

Table 1: Characteristics of analysis cohort: children identified in CRANE born with an isolated oral cleft and educational outcomes data at ages 5, 7 and 11 years

<sup>1</sup> Early Years Foundation Stage (EYFS; mean age at EYFS 5.34 years (SD 0.47)) in 2006/07, Key Stage 1 (KS1) in 2008/09, Key Stage 2 (KS2) in 2012/13; <sup>2</sup> EYFS in 2007/08, KS1 in 2009/10, KS2 in 2013/14; <sup>3</sup> Based on Income Deprivation Affecting Children Index at age 5; <sup>4</sup> In bottom decile of national distributions of attainment scores in any subject; BAME - Black, Asian and other non-white minority ethnic group.

Table 2: Association between persistent low attainment and cleft type, among children
born with isolated oral cleft in England

Cleft type	Persistent low attainment (%)	Unadjusted odds ratio (95% Cl)	P-value	Adjusted odds ratio <sup>1</sup> (95% CI)	P-value
Cleft lip	9.5%	1		1	
Cleft palate	15.6%	1.77 (1.03 to 3.03)	0.038	1.87 (1.06 to 3.27)	0.030
Cleft lip and palate	16.1%	1.83 (1.07 to 3.12)	0.028	1.81 (1.03 to 3.16)	0.038

<sup>1</sup> Logistic regression model adjusted for sex, IDACI quintile, eligibility for free school meals, ethnicity, and cohort year.

Figure 1: Mean Z-scores and 95% confidence intervals at each Key Stage comparing children with an isolated cleft to general population, by subject

EYFS – Early Years Foundation Stage, age 5 years; KS1 – Key Stage 1, age 7 years; KS2 – Key Stage 2, age 11 years

Figure 2: Mean Z-scores and 95% confidence intervals comparing children with an isolated cleft to general population, by subject, Key Stage and cleft type

EYFS – Early Years Foundation Stage; KS1 – Key Stage 1; KS2 – Key Stage 2.

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