Educational achievement in children born in the United Kingdom with unilateral cleft lip and palate

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**Scientific outline**

**Background:** Children born with oro-facial clefting have been reported to have poorer educational outcomes compared with the non-cleft population. A review of the literature was undertaken to determine which factors may account for these poorer outcomes. Future ongoing research on these outcomes and educational attainment is described. Various factors such as hearing status, speech and communication, cleft type, psychological factors and the use of special educational services by children born with oro-facial clefts have been identified as having an effect on educational attainment. Interestingly, familial studies have also demonstrated poorer educational attainment amongst unaffected siblings, indicating the presence of perhaps shared factors, both genetic and environmental. This might include family values towards education as well as socio-economic status. Reported poorer academic achievement amongst those born with a cleft may therefore be affected by confounding environmental factors.

A number of studies have reported lower educational attainment amongst children born with oro-facial clefts compared with unaffected individuals. There is not only variation according to cleft type, but attainment can be further affected by social inhibition associated with speech, hearing and communication issues, as well as familial effects. However no study in the UK has looked at educational achievements using nationalized tests for a single cleft phenotype (Unilateral Cleft lip Palate)

**Linkage between CCUK and the NPD**

National Pupil Database (NPD)

Since 2002 the Department for Education and Skills (DfES) has compiled a National Pupil Database (NPD), using the key stage test results of children undergoing state funded education (National Pupil Database, 2015). It acts as a longitudinal database with data on individual identifiable children from key stage 1 right through to key stage 5 and beyond and can be used to monitor attainment and progression (Stock et al., 2015). Subject to approval, data extracts are available to organisations or individuals for the purpose of education or wellbeing of children and conducting valuable research. For access to this data request application forms as well as information security questionnaires are required to demonstrate compliance with the data protection act and these are assessed on an
individual bases by the Data Management Advisory panel who analyse whether data release is justified.

Cleft Care UK (CCUK): CCUK is a national survey run in 2012 to assess whether cleft outcomes had improved as a result of centralization of cleft care within the UK. Data was collected from 268 children aged 5 years (born between 01/04/05 and 31/03/07) with complete UCLP. Outcomes included Audiology, speech, dental health, psychological status and health and lifestyle questionnaires, with consent for their data to be linked to educational achievement.

Methods: Linkage between NPD and CCUK
The authors will aim to obtain key stage 1 SATS results for assessments for reading, writing, speaking and listening, mathematics and science from the NPD for children that were part of the CCUK study and analyze these. This will allow comparison of KS1 results of these individuals across these 5 subject areas against national averages. This is a fantastic opportunity to understand more about the influence of cleft on educational attainment and the advantages of the CCUK method is that it contains a large sample number and the patients are all a single phenotype.

Summary: In summary, the data collected as part of the CCUK survey was from 221 children aged 5 years (and born between 01/04/05 and 31/03/07) with complete UCLP. Outcomes recorded included hearing status, speech, dental health and surgical details. As part of this study parents of children with UCLP consented for their educational attainment to be linked in the future. Therefore our aims of this project are:

1) To assess educational outcomes in children in the CCUK database and compare these against attainment for pupils without cleft at the same age
2) To assess other factors (recorded in CCUK) which may have influenced educational outcome in these children such as hearing status and speech.

The national pupil database contains data on individual identifiable children from key stage 1 right through to key stage 5 and beyond and can be used to monitor attainment and progression. By obtaining key stage 1 SATS results for assessments for reading, writing, speaking and listening, mathematics and science from the NPD for children that were part of the CCUK study educational achievement of these pupils will be directly assessed. As the NPD is a longitudinal database comparison will be possible for educational attainment of our sample with national averages to assess any possible effects of a unilateral cleft lip and palate on the educational achievement in the United Kingdom.

Key Words: cleft, confounders, educational attainment, National Pupil Database.