



Investigating the causes of cleft, the best treatments for cleft and the long-term impact of cleft on the family



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**15 Year questionnaire to parents and young people – COMING SOON!**

You may recognise some of the questions from the last questionnaire you completed for us. This is because we are interested to know how things change over time. As always, if there are questions you would prefer not to answer, just leave it blank. Understanding what it is like to grow up with a cleft from your child's perspective will help us to shape health care and support for young people. Therefore, if you have consented for your child to receive questionnaires, we will also send your child their own questionnaire. As they are now 15 years old, we will be asking them questions about their wellbeing and how they feel about their cleft. Like you, they can choose which questions to answer. Feel free to get in touch if you have any questions regarding either questionnaire. As a thank you for your time, you will each receive a **£10 voucher** for every questionnaire returned.

**New funding for cleft research!**

Our work in the Cleft Collective is allowing us to follow children over time and observe what changes for families impacted by cleft lip and palate. However, we recognise that parents also want to know what to expect when their children reach adulthood. Therefore, we are really pleased to report that we have been successful in securing additional funding from the National Institute of Health Research to investigate outcomes for young adults born with cleft in the UK. Working with the 16 regional cleft teams, we will recruit young adults from across the UK to participate in this research. You can read more about this new study at <https://www.bristol.ac.uk/news/2024/february-/cleft-collective-nihr-grant.html> If you are interested in being involved, contact: [cleft-1823@bristol.ac.uk](mailto:cleft-1823@bristol.ac.uk)

**Genotyping your biological samples**

The biological samples that you donate to us go through a process called 'genotyping'. This means that we can look at your DNA (information inside your body's cells that make you who you are) to try and understand why some people are born with a cleft and others are not. We have just finished genotyping over 6600 samples which means the data produced from this process will soon be available for researchers to apply to use to find out more about what causes cleft.



**Transforming faces**

In January, our Chief Investigator, Professor Yvonne Wren, was pleased to meet with representatives of the Canada based charity Transforming Faces. Neeti Daftari, who is the Program Manager for Global Initiatives, and Hugh Brewster, the Executive Director of the charity, discussed possibilities for collaboration with potential for impact in low and middle income countries.



**How many participants do we have in the study?**

We now have over **11,000 participants** from over **4000 families** in the study. We are so grateful to our fantastic participants and the NHS research nurses and cleft teams who are helping us to recruit.

## Latest published findings.....

1. In collaboration with Craniofacial Australia, we examined different antibiotic prescribing routines during and after surgery and their impact on developing a fistula (a break down in the palate after palate surgery). We found that the type of antibiotic and the number of doses do not appear to affect fistula formation. We would support further research in this area. More info can be found here:

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10846777/>

2. Data from three studies (the Cleft Collective, Cleft Care UK and the Clinical Standards Advisory Group) were used to investigate if there are differences in child outcomes at age five between children born with either a cleft on the left side or those born with a cleft on the right side (unilateral cleft lip and palate, UCLP). Weak evidence was found to suggest a difference in speech, hearing and psychological outcomes between the different sided UCLPs, however the findings were inconsistent across the different studies. Read more here:

<https://onlinelibrary.wiley.com/doi/10.1111/ocr.12747>

# Research update

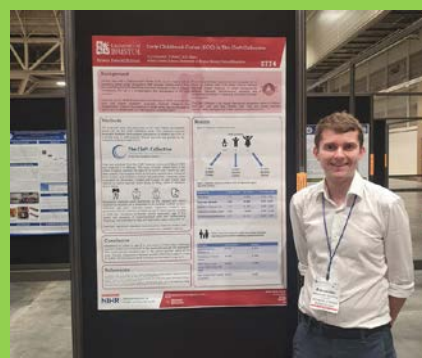
## Impact of the pandemic on early speech and language development of children born with a cleft. (Research funded by CLEFT Bridging the Gap charity)

The study used data from the Cleft Collective parent questionnaires and speech and language therapy assessments at ages 18 to 24 months to determine if the COVID lockdowns and social distancing had negatively affected speech and language development in children born with cleft. We found that there was no difference in the early speech and language skills of children who were aged 18 months before the first lockdown and those who reached 18 months of age between March 2021 and July 2022. This is a reassuring finding, though it is important to note that we were not able to look at all aspects of speech and language development and the number of children in the lockdown affected group was small, therefore, reducing the precision of the results. There will also have been variation in the extent of social distancing that participants were exposed to.



## IADR conference

Alex Gormley attended the International Association for Dental, Oral and Craniofacial Research conference in New Orleans in March 2024. Alex was presenting initial data on the prevalence of tooth decay (caries) of children in the Cleft Collective and identifying relevant risk factors for this. Alex had some initial discussions with potential collaborators in the US and looks forward to hopefully developing these relationships for further studies using Cleft Collective data.



## European Paediatric and Perinatal Epidemiology Conference, Stockholm, September 2023

Amy Davies, from the Cleft Collective, presented a poster which used data from the Cleft Collective to explore whether there were differences in the percentage of a range of structural and functional anomalies, occurring alongside a unilateral cleft, between left and right sided cleft lip with or without palate. Preliminary results suggest there may be a difference in the percentage of vision difficulties, with children born with a right sided cleft lip and palate experiencing a higher percentage of vision difficulties than children born with a left sided unilateral cleft lip and palate. Further research needs to be undertaken to explore this association further.

