



The Cleft Collective

Closing the Gap in Cleft Research

A Scar Free Foundation Initiative

One of the largest cleft lip and palate research programmes



Newsletter from the Bristol research team

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

The Underwood Trust

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A map to show where members of the Cleft Collective team have spoken about the study or shared our research findings, either in person or virtually.



Craniofacial Society of Great Britain and Ireland Conference 2023 in Cardiff

Once a year, cleft clinicians and researchers around the UK come together to share best practice and discuss cleft research. The Cleft Collective were able to present our latest findings and give an update on how well the study was doing. We'd also like to thank the Cleft Clinical Excellence Networks (speech and language, surgery, psychology, dentistry, nursing, orthodontics and audiology) for time in their busy meetings for us to talk to them about how they can use Cleft Collective data for their own research! The image is of our Chief Investigator Dr Yvonne Wren giving our update.



How many participants do we have in the study?

We now have **10601 participants** from **3788 families** in the study! This is such an amazing achievement, and we'd like to thank all of the families that have consented to be part of the Cleft Collective.

Welcome to Elizabeth!

Elizabeth has recently joined our team as a research fieldworker. Elizabeth's role will be to help us check that all the important information regarding the study children is correct.

For example, do we know what their cleft type is? When did they have their surgery?

Elizabeth will be working with the cleft teams to make sure that we get it right!



American Cleft Palate Craniofacial Association Conference 2023 in Raleigh, North Carolina

Professor Sarah Lewis and Dr Lucy Southby both gave presentations on their research using data from the Cleft Collective. Professor Lewis talked about other issues seen in children born with a cleft and the difference between children who have been diagnosed as having a cleft with a syndrome and those without. Dr Southby talked about early language development among children born with a cleft whose first 18 months were impacted by the pandemic. The conference was an opportunity to connect with collaborators in the areas of speech and genetics research in the USA.

Have any questions for us? Want to check your status in the study or recently moved?
Email us: cleft-collective@bristol.ac.uk Call us: 0117 3310025 Text us: 07799072093

Research update

Meet Nitisha Narayan (cleft surgical fellow with the South West Cleft team)

I'm grateful to have been given an opportunity to work with the Cleft Collective as part of my fellowship with Craniofacial Australia which is an Adelaide based charity that funds research in Cleft and Craniofacial surgery all over the world. (<https://www.craniofacial.com.au/>)



This year I have used the Cleft Collective data to explore the rate of weight gain in children with cleft palate. Following the Clinical Standards Advisory Group study in 1998, there was a restructuring of cleft services which led to early input from cleft specialist nurses on feeding practices in babies with cleft palate. We wanted to see how this had impacted on children's growth over the last 20 years and what factors could be affecting it. The data showed significant improvement in babies' gaining weight for those with syndromes and Robin Sequence. We aim to collect more data on this in the coming months and look forward to publishing our completed analysis.

I have also started another project on validating how we measure the cleft palate width in the operating theatre. Wider cleft palates are related to worse speech and surgical outcomes and therefore it is important to make sure surgeons all measure the width the same way. Our research work was presented at the Annual Scientific Cleft meeting in Cardiff and the Royal Australasian College of Surgeons meeting in Adelaide this year and was very well received.

Meet Alex Gormley

Alex is a dentist and clinical research fellow with an interest in the prevention of tooth decay development. He was awarded a fellowship from the NIHR to undertake his PhD with the Cleft Collective team joining in November 2022. Alex's research study is called HARMONY: HeAlthier sMiles fOR childrenN with cleft bY improving tooth decay prevention and management. A previous study called Cleft Care UK revealed that there had been no improvement in levels of tooth decay in children with cleft since UK cleft services were centralised from 1998 onwards. Alex aims to identify the reasons behind this and to develop an effective intervention to reduce the burden on children with cleft and their families. The research uses the Cleft Collective dataset to identify predictors for developing tooth decay and involves talking to children, their families, and dental workers to find out what works well and what can be improved.



CLEFT Bridging the Gap charity funding

Lucy Southby, Amy Davies and Yvonne Wren together with Sharon Baker and Helen Extence from the Welsh Cleft Centre and Neil Brierly from the West Midlands cleft service were awarded funding by the CLEFT Bridging the Gap charity at the end of 2022 to use Cleft Collective data to explore whether the pandemic may have had an impact on the early speech and language development of children born with a cleft. This work is ongoing.

Funding for Cleft Collective team member Amy Davies

Amy Davies has been awarded funding by the University of Bristol Academic Career Development Fund to write a series of papers on cleft which will contribute towards Amy's PhD. Amy will use Cleft Collective data to answer important research questions looking at other conditions which may be associated with different cleft types.



Latest research paper

This paper used Cleft Collective data to explore the percentage of children with Robin sequence who also had a syndrome and whether they needed more care. Twenty-eight percent of children with Robin sequence also had a syndrome and they were much more likely to need extra help with their breathing compared to children with Robin sequence but without a syndrome.

The full research paper can be found here: <https://adc.bmj.com/content/108/1/42.long>