

Study calls for better support for adults born with cleft lip and palate

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Many thousands of adults across the UK and the world are living with a cleft lip and/or palate, and yet many are unaware of the support that is available to them. Routine cleft care normally concludes around the age of 18 years. As a result, little is known about the longer-term outcomes of those living with cleft lip and/or palate.

The study by Nicola Stock, research psychologist from UWE Bristol's Centre for Appearance Research, will be published shortly in the *Cleft Lip and Palate-Craniofacial Journal*.

The research has influenced this month's Cleft Awareness Week and forms part of The Cleft Collective, the world's largest [cleft](#) lip/palate research programme led by the Universities of Bristol and Manchester, which aims to address the genetic and environmental causes of cleft, the best treatments for cleft and the psychological impact of cleft.

Nicola conducted in-depth individual interviews with 52 adults from across the UK, about their experiences of growing up with the condition. Nicola's research shows that although most adults adjust well to having a cleft, many require

additional information, further treatment and psychological support well into their adult years.

Nicola Stock said: "I have been working in the area of [cleft lip](#)/palate for several years now, and have seen an increase in research investigating the impact of cleft on parents and children. However, until now the views and experiences of adults with the condition have been relatively neglected.

"Before the reorganisation of cleft care in the UK a number of years ago, many children born with cleft were given sub-optimal treatment and no psychological support. My research demonstrates that adults currently living with the condition believe care to have dramatically improved, and may wish to have further surgery to improve their facial appearance and function. Due to the genetic component involved in clefting, adults who are hoping to start their own family may also require information and support regarding the heritability of cleft.

"It is vital that psychological support be available to adults with cleft, to help them cope with any ongoing difficulties, and to ensure they have realistic expectations of further treatment."

Nicola's research has helped to inform this year's campaign for Cleft Awareness Week, which is focusing on support for adults with cleft. The campaign (10 – 18 May 2014) is led by the Cleft Lip and Palate Association (CLAPA), the only charity dedicated to supporting those affected by cleft and their families across the UK.

One of the [adults](#) taking part in the study commented, "Nicola's work is an invaluable piece of information that will enhance awareness of clefts among mothers, fathers, family members, parents expecting a baby and those with clefts themselves.

"I found myself totally relaxed to share my own experiences of being born with a [cleft lip and palate](#)

and the journey from baby to teenager to adult... I did not share with anyone, even my own family until I joined CLAPA as a volunteer in 2012 and at the age of 62 met and spoke to another person with cleft for the first time in my life! It was very liberating and now I want to help as many people who may need the support that I never had.

"I was delighted that CLAPA chose Adults as their theme for this year's Awareness Week. This research will stand the test of time and help people recognise that there is a lot care and support available. I wish to give thanks and credit for Nicola's efforts and the support of CLAPA and NHS Cleft Teams around the UK who supported the study."

Rosanna Preston, Lead on User Involvement at CLAPA, said: "CLAPA is a membership association supporting people affected by cleft lip and/or palate. Our activities are directly influenced by our members and it's important that we support all people affected by cleft."

More information: A summary of Nicola Stock's research findings is available from The Cleft Collective website: www.bris.ac.uk/dental/cleft-collective/news/2014/31.html

Provided by University of Bristol

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