Interview

Interview with Yvonne Wren, Professor of Speech and Communication at the University of Bristol

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With cleft lip and/or palate (CLP) affecting approximately 1 in 800 live births, it is one of the most common congenital conditions in the UK. Evidence based research and multidisciplinary teams are essential to helping these patients overcome the complex medical, social and psychological challenges they may face as a result of the condition. With her wealth of experience and research, Yvonne Wren, Professor of Speech and Communication at the University of Bristol, is at the forefront of CLP research. Yvonne has been Chief Investigator of The Cleft Collective Cohort Study since 2020; its aims are to 'investigate the biological and environmental causes of cleft, the best treatments for cleft and the impact of cleft on those affected and their families'. In this interview, Yvonne shares with us her journey into research, common challenges faced by CLP patients, the impact of the Cleft Collective research to date, and finally how best primary care practitioners can support CLP patients.

Tell us a little bit about you and your journey into your current research.

I always liked the idea of a career in research when I was first qualified but I thought it was a pipe dream, the kind of thing that people like me didn't do.

My first degree was in Speech Pathology at the University of Manchester and that qualified me to work as a speech and language therapist. I worked in clinical roles in hospitals and community for ten years before taking up an opportunity to do a funded PhD at Bristol Speech and Language Therapy Research Unit, which was then based at Frenchay Hospital. That coincided with the births of my two older children and so took five years to complete, after which I did the usual route of multiple fixed term research associate contracts. I worked part-time during most of this period and had my third child and then applied for an NIHR PostDoc Fellowship. I was one of few who were not medics or dentists applying to that scheme and was thrilled to hear I had been successful.

This was a pivotal time for me as my research up to that point had been focused on children with speech sound disorder. During the NIHR Fellowship, I became involved in the Cleft Collective and set up the speech substudy. Through this, I became more involved with the clinical and patient communities in the field of cleft lip and palate, and this led me to taking on a more multidisciplinary role across the Cleft Collective as well as establishing processes for robust Patient and Public Involvement (PPI) for the study.

Now I lead the Cleft Collective and also the new Programme Grant Cleft@18-23. But my roots in speech and language therapy are still evident through the work I lead outside of the University of Bristol with colleagues at North Bristol NHS Trust and Cardiff Metropolitan University.

What are some common speech and communication challenges faced by individuals with cleft lip and/or palate?

When a child is born with a cleft palate, they are unable to close off the nasal cavity during speech. We do this all the time without realising – except when we make the nasal sounds 'm', 'n' and 'ng'. Without the facility to close off the nasal cavity, speech can sound hypernasal but also the consonants that require oral pressure cannot be produced. These are the sounds 'p', 'b', 't', 'd', 'k', 'g', 'f', 'v', 's', 'z', 'sh', 'zh', 'ch' and 'j'.

Surgery to repair the palate makes it possible for the oral and nasal cavities to be separated which is important for feeding as well as speech. However, it doesn't mean that there will be no future problems with speech.

As a child grows, sometimes a hole (fistula) can form in the palate where air can escape and which can impact speech. In other cases, the gap between the pharynx and the soft palate (the moveable muscle part at the back of the palate) becomes too great and the soft palate can no longer make contact with the back of the throat to close off the nasal cavity. At other times, the original repair of the cleft may break down. In each of these cases, further surgery is needed.

Children born with a cleft palate can also have articulation problems which is when the way in which they produce speech sounds in the oral cavity is different to others. There are characteristic features of articulation associated with a cleft palate and often a child will

produce some speech sounds such as 't' or 's' further back in the mouth or in a different manner to usual. This will alter how their speech sounds and might impact their intelligibility. Children – and adults – who show these characteristics need speech and language therapy to help them make changes to their speech.

Children who are born with a cleft lip and without a cleft palate have fewer problems with their speech though some might show a few difficulties with the sounds that are produced with the lips such as 'p', 'b' and 'm'. Most of the time however, children born with only a cleft lip will sound like other children of the same age.

How does your research address these challenges to enhance therapeutic interventions?

In the Cleft Collective, we are collecting data on surgical and speech and language therapy and dental interventions. Interventions vary from one child to the next depending on how they present – but there are some common elements. By collecting data on a large number of children – as we do in the Cleft Collective – we are able to determine which interventions are associated with better outcomes. In order to do this, we collect data on outcomes as well. This includes patient reported outcomes but also outcomes measured at clinical assessments and audit visits. There are many outcomes which are important in the clinical care of individuals born with a cleft. As well as speech, facial growth and appearance are important as is oral health and well-being. We collect data on each of these outcomes as well as important confounders such as socio-economic status and presence of an identified syndrome.

What are some key findings from your research and how have they influenced the cleft lip and palate patients and their families?

Some of our research has a direct impact on how we care for children born with cleft lip and palate and their families today. For example, during the COVID lockdowns, data we collected from families about their experiences of receiving support from their regional cleft team remotely were used to inform care and change practice at some of the cleft centres. In other research using Cleft Collective data, we found that the lockdowns had not had a negative impact on the development of children's speech and language skills, which was reassuring to both clinical teams and to families.

In other work, our research is helping to build a picture which in time will increase our knowledge of what causes clefting. Using genetic data which was extracted from the biological samples collected from children and their parents, we have identified new genes for cleft. However not everyone who has the gene has a cleft so we know that there must be some environmental factors which cause the gene to be activated. We will use the data we have collected in the Cleft Collective to determine which lifestyle factors are important in the relationship between the environment and genes. With this information, we can provide public health advice to reduce the likelihood of a child being born with a cleft.

As an expert in the field, what do you think are some key things dentists and wider clinicians should be aware of when treating cleft lip and palate patients?

Individuals who were born with a cleft of the lip or palate or both have experienced a lifetime of clinical care. From the moment they were born – or even before – they have received specialist care from a multidisciplinary team. Therefore, even if they present with symptoms or features which appear common to the general population, their experience of them might be different. So, in many cases, if their needs are related to their speech, their teeth, their well-being, their hearing or their appearance, it is important to consider whether a re-referral back to their specialist cleft team would be appropriate.

Yet of course, an individual who was born with a cleft is much more than just their cleft. So, understanding who they are and what is important to them will be unique as with any other patient. The key thing therefore is to listen and observe. Our work with the patient community has taught us that sometimes as clinicians we think we know what a patient needs – but if we ask them, we might learn that while we thought they were concerned about their appearance, it was actually their hearing that was bothering them.

What are the upcoming goals planned for the Cleft Collective?

The Cleft Collective is a resource – and our primary goal is to continue to grow the resource so that it can be the best possible. As a study team, comprising operations and research staff, we are keen that people know that the Cleft Collective is available for them; that it has a huge dataset which is still expanding; and that it can be accessed and used by simply completing our proposal form.

We have a lot of dental information in the Cleft Collective, both from parent and participant questionnaires and also from clinical assessment. We are keen for dentists and orthodontists to use the data to ask clinically relevant questions.

To find out more, look at our website https://www.bristol.ac.uk/dental/cleft-collective/ or get in touch with us at cleft-collective@bristol.ac.uk

And if you have a cleft yourself, you could get involved in Yvonne's research. To find out more, go to https://www.bristol.ac.uk/dental/research/epidemiology-health-services-research/cleft18-23-study/