

The Cleft Collective Cohort Study – a global resource for research into the causes and best treatments for cleft

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Abstract:

Research in the field of cleft lip and palate is challenged by small sample sizes, variations in treatment, and the need for longitudinal follow up. Yet understanding the causes of cleft, the best treatments for cleft and outcomes for those affected is vital to our management of this population throughout the world. The Cleft Collective Cohort Study was set up to address these challenges¹. With over 12,000 participants from more than 4,200 families of children born with cleft, the Cleft Collective resource is unmatched in the breadth and depth of data collected. By following these patients from birth to adolescence, we have collected a baseline of genotype and detailed phenotype data supported by information on environmental and lifestyle factors alongside parent/patient self-report and clinical data. The data available covers a broad spectrum of areas relevant to analysis of treatment effectiveness and outcomes including demographic, biological, genetic, surgical, dental, speech, audiology and psychological variables. The Cleft Collective resource is available for researchers across the globe to use. To date, over 60 proposals have been approved to investigate a wide range of questions with impact for improved understanding of the nature of cleft, the genes involved in its formation, the impact of variations in treatment such as relieving incisions in surgery and post-operative antibiotics, the norms for intelligibility and presence of behavioural problems.



Biography:

Yvonne Wren is Professor of Speech and Communication at the University of Bristol, Professor of Speech and Language Therapy at Cardiff Metropolitan University in Wales and Senior Research Leader for Health and Care Research Wales. She is also Director of Bristol Speech and Language Therapy Research Unit, where she leads a team of researchers working across the field of communication impairment.

Professor Wren leads the research in cleft lip and palate at Bristol Dental School, University of Bristol. As part of this role, she leads two large national studies – the Cleft Collective Cohort Study and Cleft@18-23. The Cleft Collective Cohort Study is a resource of data from over 12,000 participants comprising children born with a cleft and their families. The data includes biological samples and genotypes, clinical data and self-report data from the families. The resource is available for any researcher or clinician to use from anywhere in the world <https://www.bristol.ac.uk/dental/cleft-collective/>. Cleft@18-23 is a new study which is investigating variation in outcomes for young adults born with a cleft lip or palate since centralisation of care in the UK.

In addition to her work in cleft lip and palate, Professor Wren is Chief Investigator of the MISLToe_SSD study, which has led to the development of a core outcome set for use with children with speech sound disorder, and also Prosiect Pengwin, a Welsh Government funded study to develop a new programme for monitoring early speech, language and communication development in children growing up in Wales. She was previously chair of the Child Speech Committee for the International Association of Communication Sciences and Disorders and also set up the UK and Ireland Child Speech Disorder Research Network. She was elected Fellow of the Royal College of Speech and Language Therapists in 2022.