

Project Number: CC019

Title: A review of the utilisation of the Cleft Lip And Palate Association (CLAPA)'s services by the cleft community

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Scientific Outline:

As part of CLAPA's commitment to diversity and ensuring that their services are accessible to all members of the cleft community, they plan to understand more about the people who choose to access or not access their services. CLAPA currently collects data from their service users to understand which services are utilised, but they recognise this data is biased as it is only collected from those who choose to use CLAPA's services. CLAPA understands that there may be a significant portion of the cleft community who either are unaware of their services, or conscientiously choose not to use them. The Cleft Collective cohort study collects data through the parents' questionnaires regardless of whether they interact with CLAPA or not.

The Cleft Collective has been collecting quantitative data on how parents of children with a cleft use or don't use CLAPA's services for a number of years. Demographic information is also collected on the people completing questionnaires. CLAPA would like to access this data to understand the services that are most and least used, as well as the demographics of the people accessing them. This data will help to guide both future service delivery strategy and diversity outreach efforts. In particular, CLAPA would like to use this data to compare how people answer the questions about their use of CLAPA's services with their demographic information to see if there are certain groups which CLAPA is failing to engage and/or deliver a satisfactory service to.

Using data from parent questionnaires CLAPA will determine what proportion of Cleft Collective questionnaire responders have and have not received support from CLAPA. CLAPA support (Y/N) will then be described by characteristics such as cleft type, pseudonymised region, ethnicity, country of birth, age at conception, parity and family history of cleft. Associations between these characteristics and whether support was received will be explored using analysis methods for comparing groups. These methods will include chi-squared tests for categorical characteristics, t-tests for normally distributed continuous characteristics and Mann-Whitney U tests for non-parametric continuous characteristics. Where associations are found further analysis will take place using binary logistic regression to explore relationships between characteristics and the use of CLAPA.

Restricting the analysis to families who have received support from CLAPA they will describe services used and parental satisfaction of the support received. Using similar analysis methods to those described above CLAPA will further explore whether there is a demographic difference in services used and parental satisfaction by identifying any associations or relationships which may be present.