

Project Number: CC003

Title: What is the impact of cleft lip/palate on families' quality of life, and how might healthcare and support be improved?

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Scientific Outline:

This study will collect qualitative data from families already enrolled in The Cleft Collective Birth Cohort. Individual telephone interviews lasting up to 90 minutes will cover a range of topics relevant to the psychological needs of the parents, as well as the social, emotional and cognitive development of the child. If further funding applications are successful, these spoken narratives will later be combined with the quantitative data that is already being collected, to produce pioneering mixed-methods research with significant potential to improve the support that affected children and their families receive, in line with the James Lind Alliance priorities.

It will likely not be possible to carry out interviews with every family, due to large numbers and time constraints. Therefore, families will be invited to participate in an interview based primarily on the 'completeness' of the questionnaire data already received; i.e. has the parent completed a questionnaire at the majority of the key time points (post-diagnosis, 18 months, 3 years)? Where possible, an equal number of mothers and fathers will be sought, and a fair representation of key demographics variables, such as the child's cleft type, will be attempted. Due to financial limitations and time constraints, parents will need to possess a good level of spoken English to participate in the interview study.

Parents will be approached to take part in the interview study by email and/or via an A5-sized postcard within an addressed envelope. The study may also be advertised more generally on relevant websites and social media. Interviews will be carried out by the Chief Investigator, and by a Research Associate.

Initially, the researcher(s) will need support to identify cohort-enrolled parents who are eligible to participate. Access to these families' information, including contact details, will then be requested. The Cleft Collective team will be kept informed of any progress and any challenges which may arise.