

**Project Number:** CC007

**Title:** Satisfaction with healthcare among parents of children born with cleft lip and/or palate

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**Scientific Outline:**

Children born with a cleft lip and/or palate (CL/P) will require several interventions during their first 18 months of life. This may include respiratory and feeding support, surgery to repair the cleft, and/or the insertion of grommets, among others. In the UK, CL/P treatment and related support is provided by the family's geographically closest specialist multidisciplinary team. Due to the complex nature of the care pathway, and the potential for suboptimal care to impact negatively on parental wellbeing (Vanz and Ribeiro, 2011), parents' satisfaction with the healthcare which they and their children receive in the first 18 months is crucial.

Unfortunately, previous studies of the degree to which parents are satisfied with UK CL/P services have been limited by cross-sectional data collected from small samples and/or from single sites. Further, several of these studies were carried out before, or around the time of centralisation, and so may no longer be accurate. Previous research in this area has also tended to focus predominantly on the views of mothers, and has largely neglected the father's perspective (Nelson and Kirk, 2013).

While parents may hold positive views of the service overall (Turner et al., 1997), a number of unmet needs may be unaccounted for in CL/P research (Nelson and Kirk, 2013), and thus standardised, detailed assessment of healthcare satisfaction is warranted. The PEDSQL Healthcare Satisfaction measure is one such comprehensive instrument, capable of eliciting specific information regarding parents' satisfaction with information provision, family inclusivity, health professionals' communication and technical skills, and how well parents' emotional needs have been addressed, in addition to providing an overall satisfaction score.

As well as assessing parents' satisfaction with healthcare following a diagnosis of CL/P in their child, according to baseline (postnatal) questionnaires (n = ~1500), the inclusion of data collected at 18 months (n = ~400) will allow for assessment of parental satisfaction over time, analysis of factors which may be associated with satisfaction, and longitudinal investigation of the impact of satisfaction on parents' psychological health. Specifically, the following four research questions will be addressed:

- How satisfied are parents with the level of healthcare they/their child has received at baseline?
- How does healthcare satisfaction change over time (PN – 18 months)?
- What factors are associated with parents' level of healthcare satisfaction?

How does parents' PN level of healthcare satisfaction impact upon parental psychological wellbeing at 18 months?

In the first instance, this study will analyse cross-sectional data obtained via parent-reported baseline (postnatal) CC questionnaires, in order to assess parents' satisfaction with the healthcare they/their child has received. The anticipated sample size for this aspect of the study (based on the current postnatal questionnaire return rate) is ~1500 mothers and fathers of children with CL/P.

In addition, this study will analyse data collected in the 18 month questionnaire, to investigate how parents' healthcare satisfaction may change over time, what factors are associated with parents' healthcare satisfaction, and the impact of PN healthcare satisfaction on parents' psychological wellbeing at 18 months. The anticipated sample size for this aspect of the study (based on the current 18 month questionnaire return rate) is ~ 400 mothers and fathers of children with CL/P.