The Cleft Collective
Closing the Gap in Cleft Research
A Scar Free Foundation Initiative

Project Number: CC008

Title: Parental psychological adjustment following a diagnosis of cleft lip and/or palate and associated risk factors

PI: Dr Nicola Stock

Affiliation: The University of the West of England

Approval Date: July 2017

Scientific Outline:

The birth of a child with a congenital craniofacial condition, such as a cleft lip and/or palate (CL/P), poses a number of challenges for parents. In the weeks following a diagnosis, parents may express guilt at having done something to cause the cleft, and grief at the loss of the imagined 'perfect' child (Nelson et al., 2012). Parents must also process a wealth of new information, grapple with feeding difficulties, come to terms with their baby's condition, and manage the awkward or intrusive reactions of others (Bessell et al., 2011; Nelson et al., 2012; Stock and Rumsey, 2015). Further, parents will be expected to engage their newborn in a long-term, multidisciplinary treatment pathway.

Previous research has demonstrated that the quality of support the family receives at this early stage is crucial in facilitating psychological adjustment, and can have a long-term impact on how families cope with the challenges ahead (Vanz and Ribeiro, 2011). In addition, a research priority-setting exercise carried out by the James Lind Alliance (Petit-Zeman and Cowan, 2013) identified the 'optimal type and timing of psychological support for children and their families' to be the most important unaddressed research area. In spite of a clear need for robust psychological support from the point of diagnosis, no evidence currently exists to support any form of psychological intervention for families affected by CL/P (Norman et al., 2015). This is partially due to existing studies being compromised by a variety of methodological limitations, including, crucially, a lack of large samples, and a paucity of comprehensive patient-reported data (Hunt et al., 2005; Stock and Feragen, 2016).

The proposed study would carry out a comprehensive quantitative analysis of all existing data pertaining to parental psychological wellbeing, in order to provide an important first step toward understanding the extent of the impact of CL/P on families, as reported by the parents themselves. Specifically, this study will address:

- What is the psychological impact of a diagnosis of CL/P on the family?
- How does parental psychological adjustment change over time (PN-18 months)?

What factors are associated with parental psychological adjustment?

This study will analyse cross-sectional data obtained via parent-reported baseline (postnatal) CC questionnaires, in order to assess parents' wellbeing following their child's diagnosis. 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, data from the 18 month questionnaires will be accessed (n = ~400) to investigate how parental adjustment changes over time, and potential risk factors for psychological distress.