

## The Cleft Collective

### Psychology measures and associated time points

**February 2023**

TIME POINT	TOPICS	MEASURES
Diagnosis (antenatal/postnatal recruitment)	Impact of diagnosis on family; satisfaction with healthcare received; parents' outlook on life; parents' level of perceived stress; parents' levels of anxiety and depression; cleft-specific issues	PEDSQL Family Impact; PEDSQL Healthcare Satisfaction; Revised Life Orientation Scale; Perceived Stress Scale; Hospital Anxiety and Depression Scale; our additional cleft-specific questions
18 months	Impact of cleft on family; satisfaction with healthcare received; parents' level of perceived stress; parents' levels of anxiety and depression; child's development; cleft-specific issues	PEDSQL Family Impact; PEDSQL Healthcare Satisfaction; Perceived Stress Scale; Hospital Anxiety and Depression Scale; Ages and Stages (cognitive and social-emotional); our additional cleft-specific questions
3 years	Impact of cleft on family; satisfaction with healthcare received; parents' outlook on life; parents' level of perceived stress; parents' levels of anxiety and depression; child's development; cleft-specific issues	PEDSQL Family Impact; PEDSQL Healthcare Satisfaction; Revised Life Orientation Scale; Perceived Stress Scale; Hospital Anxiety and Depression Scale; Ages and Stages (cognitive and social-emotional); our additional cleft-specific questions
5 years	Impact of cleft on family; satisfaction with healthcare received; parents' level of perceived stress; parents' levels of anxiety and depression; child's development; cleft-specific issues	PEDSQL Family Impact; PEDSQL Healthcare Satisfaction; Revised Life Orientation Scale; Perceived Stress Scale; Hospital Anxiety and Depression Scale; Ages and Stages (cognitive and social-emotional); Strengths and Difficulties Questionnaire; our additional cleft-specific questions
8 years	Impact of cleft on family; satisfaction with healthcare received; parents' outlook on life; parents' level of perceived stress; parents' levels of anxiety and depression; child's development; cleft-specific issues; teasing and bullying	PEDSQL Family Impact; PEDSQL Healthcare Satisfaction; Perceived Stress Scale; Hospital Anxiety and Depression Scale; Strengths and Difficulties Questionnaire; our additional cleft-specific questions; extracts from the SIG parent questionnaire at age 10
10 years	Impact of cleft on family; satisfaction with healthcare received; parents' level of perceived stress; parents' levels of anxiety and depression; child's development; cleft-specific issues; teasing and bullying	Life Events Scale; PEDSQL Family Impact; PEDSQL Healthcare Satisfaction; Strengths and Difficulties Questionnaire; our additional cleft-specific questions; Moods and Feelings; Screen for

		Child Anxiety Related Disorders (SCARED); CHASQ; Harter Scales
12 years	Impact of cleft on family; satisfaction with healthcare received; child's development; child's levels of depression; child's levels of anxiety; parents' levels of anxiety and depression; parents' level of perceived stress; child's social skills; child's emotions and worries; cleft-specific issues; teasing and bullying	PEDSQL Family Impact; PEDSQL Healthcare Satisfaction; Strengths and Difficulties Questionnaire (parental report); Moods and Feelings; Screen for Child Anxiety Related Disorders (SCARED); Hospital Anxiety and Depression Scale (HADS); Perceived Stress Scale (PSS); Social Responsiveness Scale (SRS-2); The National Institute of Mental Health (NIMH) Emotions and Worries; Clinical Excellence Network Questionnaire (CEN-Q; parent report); CHAS-Q; Harter Scales; CEN-Q (child report); SDQ (child report)