Study number:		CLEFT CARE UK 2010-2012
A1 ID Number		
A2 Today's date		
	YOU AND YOUR FAMILY	
B1 Child's date of bi	rth:	
B2A Is this child:	Male Female	
B3A Are you the child	d's: Mother Father	
	Someone else Who, please specify	ВЗАЗА
B4 How old were you	u when this child was born?	
B5 How old was your	r partner when this child was born years	
B6A How would you	describe your race or ethnic group? (Please tick on	ly one)
White	1 Pakistani 5	
Black / Caribbean	2 Bangladeshi 6	
Black / African	3 Chinese □7	
Indian	4 Other (please describe)8	B6A8A

B7 Who currently lives at home with you? Please list everyone in the box below and their relationship to you (eg son, daughter, husband (or wife), partner, step-son and so on

	Relationship to you?	Age	
А	1		years
В	1		years
С	1		years
D	1		years
Е	1		years
F	1		years
G	1		years
Н	1		years
I	1		years
J	1		years
B8	How many children do you have living with you?		

Study number:	CLEFT CARE UK 2010-2012
B9 What is your highest educational qualification?	
Vocational O level/GCSE A level	Degree
B10 What is your occupation?	
B11A Are you currently (please tick only one)	
Employed by somebody else (part-time)	1
Employed by somebody else (full -time)	1
Self-employed	2
Not employed outside the home (looking for work)	3
Not employed outside the home (not looking for work)	5
B12 What is the first part of your postcode?	
B13A Thinking of other people in your family (and your partner's), is there cleft lip, cleft palate or both cleft lip and palate? YES NO	e anyone else who has a
B14 If yes, please tell us how they are related to your child (for example:	child's older sister, child's
younger brother, child's grandmother (mother's mother), child's aun	t (father's sister) and so on
A	

В	
С	
D	
Е	
F	
G	
Н	

YOUR CHILD

Here are some statements about the things children do.

For each statement please TICK A BOX to show how often your child behaves in that way

		Never	Rarely	Sometimes	Often	Always
C1A	S/he tends to be shy	1	2	3	4	5
C2A	S/he tends to cry easily	1	2	3	4	5
C3A	S/he likes to be with people	1	2	3	4	5
C4A	S/he is always on the go	1	2	3	4	5
C5A	S/he prefers playing with others rather than alone	1	2	3	4	5
C6A	S/he is somewhat emotional	1	2	3	4	5
C7A	When s/he moves about s/he moves slowly	1	2	3	4	5
C8A	S/he makes friends easily	1	2	3	4	5
C9A	S/he is off and running as soon as s/he wakes up in the morning	1	2	3	4	5
C10A	S/he finds people more stimulating than anything else	1	2	3	4	5
C11A	S/he fusses and cries	1	2	3	4	5
C12A	S/he is very sociable	1	2	3	4	5
C13A	S/he is very energetic	1	2	3	4	5
C14A	S/he takes a long time to warm to strangers	1	2	3	4	5
C15A	S/he gets easily upset	1	2	3	4	5
C16A	S/he is something of a loner	1	2	3	4	5
C17A	S/he prefers quiet inactive games to more active ones	1	2	3	4	5
C18A	When alone s/he feels isolated	1	2	3	4	5
C19A	S/he reacts intensely when upset	1	2	3	4	5
C20A	S/he is very friendly with strangers	1	2	3	4	5
C21A	S/he bullies other children	1	2	3	4	5
C22A	S/he is very restless, hardly ever still	1	2	3	4	5
C23A	S/he is squirmy or fidgety	1	2	3	4	5
C24A	S/he destroys her own things or those belonging to others	1	2	3	4	5
C25A	S/he fights with other children			2		

Study number:

		Never	Rarely	Sometimes	Often	Always
C26A	S/he is not much liked by other children	1	2	3	4	5
C27A	S/he worries about many things	1	2	3	4	5
C28A	S/he does things on her/his own. S/he is rather solitary	1	2	3	4	5
C29A	S/he is irritable, is quick to fly off the handle	1	2	3	4	5
C30A	S/he appears miserable, unhappy, tearful or distressed	1	2	3	4	5
C31A	S/he takes things belonging to others	1	2	3	4	5
C32A	S/he bites her nails or fingers	1	2	3	4	5
C33A	S/he is disobedient	1	2	3	4	5
C34A	S/he cannot settle to do anything for more than a few moments	1	2	3	4	5
C35A	S/he is afraid of new things or situations	1	2	3	4	5
C36A	S/he is fussy or over-particular	1	2	3	4	5
C37A	S/he tells lies	1	2	3	4	5
C38A	S/he likes to sit and watch TV rather than play active games	1	2	3	4	5
C39A	S/he laughs a lot	1	2	3	4	5
C40A	S/he smiles when s/he sees her parent(s)	1	2	3	4	5
C41A	S/he likes a cuddle		2	3	4	5
C42A	S/he really enjoys life	1	2	3	4	5

YOU AND YOUR CHILD

HERE ARE SOME COMMENTS THAT PARENTS HAVE MADE ABOUT LOOKING AFTER THEIR CHILDREN. FOR EACH STATEMENT, PLEASE TICK A BOX TO SHOW HOW MUCH YOU AGREE WITH EACH STATEMENT. IF SOME OF THE ITEMS ARE DIFFICULT TO ANSWER,

PLEASE CHOOSE THE ANSWER THAT COMES CLOSEST FOR YOU.

		Never	Occasionally	Quite often	Always
D1A	I blame myself when my child gets hurt	1	2	3	4
D2A	I comfort my child immediately when s/he	1	2	3	4
	cries				
D3A	I encourage my child to depend on me	1	2	3	4
D4A	I have difficulty separating from my child	1	2	3	4
D5A	I trust my child on his / her own	1	2	3	4
D6A	I let my child make his / her own decisions	1	2	3	4
D7A	I have difficulty leaving my child with a babysitter	1	2	3	4
D8A	I decide when my child eats	1	2	3	4
D9A	I use baby words when I talk with my child		2	3	4
D10A	I urge my child to try new things		2	3	4
D11A	I determine who my child will play with		2	3	
D12A	I keep a close watch on my child		2	3	4
D13A	I feed my child even if s/he can do it alone		2	3	4
D14A	I feel comfortable leaving my child with	1	2	3	4
	other people				
D15A	I protect my child from criticism	1	2	3	4
D16A	I let my child choose what s/he wants to wear	1	2	3	4
D17A	I make my child go to sleep at a set time		2	3	4
D18A	I go to my child if s/he cries during the night		2	3	4
D19A	I encourage my child to play with other		2	3	4
	children				
D20A	I give my child extra attention when s/he clings to me	1	2	3	4
D21A	I decide what my child eats	1	2	3	4
D22A	I dress my child even if s/he can do it alone	1	2	3	4
D23A	I decide when my child goes to the bathroom	1	2	3	4
D24A	I know exactly what my child is doing	1	2	3	4
D25A	I allow my child to do things on his / her own	1	2	3	4

The following statements are concerned particularly with how you feel about your child's health. As before, for each statement, please TICK THE BOX to show how much you agree. If some of the items are difficult to answer, please tick the box which comes closest for you.

		Never	Occasionally	Quite often	Always
D26A	In general my child seems less healthy than other children	1	2	3	4
D27A	I often think about calling the doctor about my child	1	2	3	4
D28A	When there is something going around my child usually catches it	1	2	3	4
D29A	I sometimes get concerned that my child doesn't look as healthy as s/he should	1	2	3	4
D30A	I often have to keep my child indoors because of health reasons	1	2	3	4
D31A	My child gets more colds than other children I know	1	2	3	4
D32A	I get concerned about circles under my child's eyes	1	2	3	4
D33A	I often check my child at night to make sure that s/he is ok	1	2	3	4

The questions below are concerned with how you feel when you are with your child. Please answer them honestly and tick the box which shows how you feel most of the time.

		Feel	Often	Sometimes	Never
		exactly	feel	feel	feel
D34A	I really enjoy this child	 1	2	3	4
D35A	I feel confident with my child	1	2	3	4
D36A	It is a great pleasure to watch my child develop	1	2	3	4
D37A	Having this child makes me feel fulfilled	1	2	3	4
D38A	I would have preferred that we had not had this child when we did	1	2	3	4
D39A	I can't bear hearing the child cry	1	2	3	4
D40A	I dislike / hate the mess that surrounds the child	1	2	3	4
D41A	I feel I have no time to myself	1	2	3	4

YOUR THOUGHTS AND FEELINGS

Below are some statements about your thoughts and feelings.

Please tick the box that best describes your experience of each over THE LAST 2 WEEKS.

		None of the time	Rarely	Some of the time	Often	All of the time
E1A	I've been feeling optimistic about the future	1	2	3	4	5
E2A	I've been feeling useful	1	2	3	4	5
E3A	I've been feeling relaxed	1	2	3	4	5
E4A	I've been feeling interested in other people	1	2	3	4	5
E5A	I've had energy to spare	1	2	3	4	5
E6A	I've been dealing with problems well	1	2	3	4	5
E7A	I've been thinking clearly	1	2	3	4	5
E8A	I've been feeling good about myself	1	2	3	4	5
E9A	I've been feeling close to other people	 1	2	3	4	5
E10A	I've been feeling confident	1	2	3	4	5
E11A	I've been able to make up my own mind about things	1	2	3	4	5
E12A	I've been feeling loved	1	2	3	4	5
E13A	I've been interested in new things	1	2	3	4	5
E14A	I've been feeling cheerful	1	2	3	4	5

The questions in this scale ask you about your feelings and thoughts during THE LAST MONTH. In each case please answer the question by putting a tick in the square which shows HOW OFTEN you felt or thought a certain way.

Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer fairly quickly. That is, don't try to count up the number of times you felt a particular way, but rather the alternative that seems like a reasonable estimate.

		Never	Almost never	Sometimes	Fairly Often	Very Often
E15A	In the last month, how often have you felt upset because of something that happened unexpectedly?		2	3	4	5
E16A	In the last month how often have you felt that you were unable to control the important things in your life?	1	2	3	4	5
E17A	In the last month, how often have you felt nervous and "stressed"?	1	2	3	4	5
E18A	In the last month, how often have you dealt successfully with irritating life hassles?	1	2	3	4	5
E19A	In the last month, how often have you felt that you were effectively coping with important changes that were occurring in your life?	 1	2	3	4	5
E20A	In the last month, how often have you felt confident about your ability to handle your personal problems?	1	2	3	4	5
E21A	In the last month, how often have you felt that things were going your way?	1	2	3	4	5
E22A	In the last month, how often have you found that you could not cope with all the things that you had to do?	1	2	3	4	5
E23A	In the last month, how often have you been able to control irritations in your life?	1	2	3	4	5
E24A	In the last month, how often have you felt that you were on top of things?	1	2	3	4	5

Please answer the following questions about your outlook on life.

Be as honest as you can throughout, and try not to let your responses to one question influence your response to other questions. There are no right or wrong answers.

		Strongly	Disagree	Neutral	Agree	Strongly
		disagree				agree
E25A	In uncertain times, I usually expect the		2	3	4	5
	best.					
E26A	It's easy for me to relax.	1	2	3	4	5
E27A	If something can go wrong for me, it will.	1	2	3	4	5
E28A	I'm always optimistic about my future.		2	3	4	5
E29A	I enjoy my friends a lot.	1	2	3	4	5
E30A	It's important for me to keep busy	1	2	3	4	5
E31A	I hardly ever expect things to go my way.	1	2	3	4	5
E32A	I don't get upset too easily.	1	2	3	4	5
E33A	I rarely count on good things happening	1	2	3	4	5
	to me.					
E34A	Overall, I expect more good things to	1	2	3	4	5
	happen to me than bad.					

Personal costs for parents/immediate family

Finally, we'd like to ask you about any **expenses** you or your immediate family members may have incurred **because of your child's cleft lip and palate**.

	<i>,</i> , , , , , , , , , , , , , , , , , ,	•					
	Since the birth of your child, did he or she receive any of the following because of his or her cleft lip and palate?	Yes*	No*	NA*		paid for it, please eximate amount When your child was aged 0-4 yea	
F1A	Educational assessment (e.g. hearing or speech assessment).	1	2	3	£1A	£1B	
F2A	Special education (e.g. speech and language lessons).	1	2	3	£ 1A	£1B	
F3A	Outside child care (e.g. babysitting by a friend or neighbour).	1	2	3	£ 1A	£1B	
F4A	Equipment or aids (e.g. feeding equipment, computer software to help with speech and language development).	 1	2	3	Type of equipment/aids 1A	Type of equipment/aids 1C	
					£ 1B	£1D	

	Since the birth of your child, have you or any member of your immediate family incurred any of the following because of his or her cleft lip and palate?	Yes*	No*	NA*	indicate appro During the past	paid for it, please oximate amount When your child was aged 0-4 years
F5A	Travel and/or accommodation expenses for your child's hospital/clinic appointments? (e.g. cost of petrol, train fares, bus fares, taxi fares, parking costs, B&B costs)	 1	2	3	f _{1A} Number of appointments attended 1B	f _{1C} Number of appointments attended1D
F6A	Other expenses for health and educational services?	1	2	3	type of expenditure	type of expenditure
					£1B	£1D
F7A	Taken time off work because of caring for your child?	 1	2	3	number of days	number of days
F8A	Suffered any loss of earnings as a result of taking time off work?	1	2	3	IA	1B
F9A	Given up work completely because of caring for your child?	1	2	3	Gross income loss £1A	Gross income loss £1B
	* Please tick as appropriate NA – not a	applicable				

Study number:

The end of the questionnaire

Thank you for taking the time to complete this questionnaire