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

ID LABEL

You and Your Child at 3 Years

Mother's questionnaire

This questionnaire is for the child's mother.

University of Bristol
University of the West of England Bristol
The Scar Free Foundation
VTCT World Class Qualifications

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(for office use only)

About this research

You are being asked to complete this questionnaire because you have chosen to participate in The Cleft Collective Cohort Studies. This research is taking place in collaboration with cleft teams in the UK to investigate the causes of cleft, the best treatments for cleft and the long-term impact of cleft on the family and the individual.

About this questionnaire

This questionnaire has seven sections:

A. **Your Child's Health** - This section asks you questions related to the health of your child
B. **Feeding Your Child** - This section asks about your experience of feeding your child
C. **Your Child's Teeth** - This section asks questions about your child's teeth and dentist
D. **Additional Questions About Your Child -** This section is additional questions not covered in any other section including childcare, sleep position and hearing
E. **Your Family** - This section asks you questions about where you live, your marital status and your other children (if applicable)
F. **Your Lifestyle** - this section asks questions about your diet, alcohol use, cigarette smoking and exercise
G. **Your Wellbeing** - the last section asks about how you have been feeling recently

<u>Please try to answer all of the questions</u>, even if some of them sound strange to you. As so little is known about the causes of cleft, we need to ask a broad range of questions about your environment and family history to help us understand what causes cleft and how we can help to support families.

When we ask questions about 'your pregnancy' and 'your child' please answer in relation to your child who was born with a cleft. Please fill out the information you can remember.

There are no right or wrong answers. If you do not want to answer a question then just leave it blank.

Some of the questions ask about your health and your lifestyle. We need to know this information to find out if any of these factors could be related to cleft lip and palate, but this does not necessarily mean that any of these factors were involved in the development of your child's cleft.

All of the answers you give us in this questionnaire will be kept anonymous.

How to fill in this questionnaire

Please use a black pen. To answer the questions please put a cross in the box like this:

If you make a mistake, shade the box in like this:

then cross the correct box.

If you are answering questions which ask you to give further details, please make sure you write inside the boxes.

Who to contact for support

If you have any questions or if you feel concerned or distressed before/after completing this questionnaire and would like some extra support, please contact your cleft team who can help.

Thank you for completing this questionnaire!

SECTION A - YOUR CHILD'S HEALTH

A1. What type of cleft was your child born with?

☐ Cleft lip ☐ Cleft lip and palate ☐ Don't know
☐ Cleft palate ☐ Submucous cleft palate

A2. Is your child's cleft unilateral (on one side of their mouth) or bilateral (on both sides of their mouth)?

☐ Unilateral ☐ Bilateral ☐ Don't know ☐ Not applicable

A3. If your child's cleft is unilateral (on one side of their mouth), which side of your child's mouth is the cleft on (when looking at your child)?

☐ Right ☐ Left ☐ Don't know ☐ Not applicable

A4. a) If your child has a cleft palate, when was this diagnosed?

☐ At the 20 week scan ☐ At birth ☐ Not applicable
☐ During a 3D scan ☐ After birth (late diagnosis)

b) If your child's cleft palate was diagnosed during a 3D scan, please give the number of weeks

☐☐ Weeks ☐ Not applicable

c) If your child's palate was diagnosed after their birth, please tell us how many years/weeks/days after

Years ☐☐ Weeks ☐☐ Days ☐☐ ☐ Not applicable

A5. Has your child had any of the following infections? **(Cross all that apply)**

☐ 0) None
☐ i) German measles
☐ ii) Measles
☐ iii) Chickenpox
☐ iv) Mumps
☐ v) Meningitis
☐ vi) Urinary tract infection (E.g. cystitis)
☐ vii) Chest infections / pneumonia
☐ viii) Recurrent ear infections
☐ ix) Other infection (please specify below)

A6. Has your child had / does your child have any of the following conditions or problems? **(Cross all that apply)**

a) Neurological / Sensory Conditions

- ☐ 0) None
- ☐ i) Epilepsy / Fits / Convulsions
- ☐ ii) Cerebral Palsy
- ☐ iii) Developmental delay
- ☐ iv) Hearing loss or impairment
- ☐ v) Glue Ear, OME (Otitis Media with Effusion)
- ☐ vi) Difficulties with vision / blindness
- ☐ vii) Other neurological condition (specify below)

b) Heart / Lungs / Immune system

- ☐ 0) None
- ☐ i) Heart condition
- ☐ ii) Lung condition
- ☐ iii) Asthma / Difficulties breathing
- ☐ iv) Allergies
- ☐ v) Immune deficiency
- ☐ vi) Other problems with heart / lungs/ Immune system (please specify below)

c) Skin / Musculoskeletal conditions

- ☐ 0) None
- ☐ i) Skin condition
- ☐ ii) Skeletal condition
- ☐ iii) Talipes (Club foot)
- ☐ iv) Spine condition
- ☐ v) Other skin / musculoskeletal condition (specify below)

d) Metabolic conditions

- ☐ 0) None
- ☐ i) Thyroid condition
- ☐ ii) Abnormal calcium levels
- ☐ iii) Blood condition
- ☐ iv) Other metabolic condition (specify below)

e) Abdominal conditions

- ☐ 0) None
- ☐ i) Severe / persistent vomiting
- ☐ ii) Severe / persistent diarrhoea
- ☐ iii) Severe / persistent gut abnormalities
- ☐ iv) Liver problems
- ☐ v) Jaundice
- ☐ vi) Failure to gain weight or grow
- ☐ vii) Other abdominal condition (specify below)

f) Kidney and bladder problems

- ☐ 0) None
- ☐ i) Kidney / bladder problems (specify) ☐
- ☐ ii) Hypospadias (males only)

A7. Does your child have problems with the development of any of the following? **(Cross all that apply)**

☐ a) Eyes	☐ f) Hands
☐ b) Ears	☐ g) Feet
☐ c) Cheekbones	☐ h) Spine
☐ d) Jaw	☐ i) Other developmental condition (please specify)
☐ e) Tongue	☐ j) None of the above

A8. Has your child been diagnosed with any of the following syndromes / genetic conditions? **(Cross all that apply)**

- ☐ a) Pierre Robin sequence (PRS)
- ☐ b) Van der Woude syndrome
- ☐ c) Treacher Collins syndrome
- ☐ d) Hemifacial Microsomy / Goldenhar syndrome
- ☐ e) Stickler syndrome
- ☐ f) 22q 11.2 deletion syndrome (also known as Velocardiofacial syndrome, Shprintzen syndrome, DiGeorge syndrome)
- ☐ g) Craniosynostosis (including Crouzon syndrome, Apert syndrome, Pfeiffer syndrome, Saethre-Chotzen syndrome)
- ☐ h) Cornelia de Lange syndrome
- ☐ i) Other syndrome / genetic condition (specify)
- ☐ j) We are currently undergoing genetic testing at the hospital
- ☐ k) None of the above

A9. Has your child been diagnosed with any other condition not mentioned above? (please specify below)

SECTION B - FEEDING YOUR CHILD

B1. Has your child had any nasal regurgitation (food coming down their nose)?

☐ Often ☐ Sometimes ☐ No

B2. Has your child had any difficulties swallowing?

☐ Often ☐ Sometimes ☐ No

B3. a) Does your child feed themselves?

☐ Yes, usually ☐ Yes, sometimes ☐ No

If yes b) How do they feed themselves? **(Cross <u>all</u> that apply)**

☐ Knife and fork ☐ Spoon or fork ☐ Fingers

B4. What does your child normally drink? **(Cross <u>all</u> that apply)**

☐ a) Water ☐ d) Squash

☐ b) Milk ☐ e) Other (please specify) ☐

☐ c) Fruit juice

B5. What does your child usually drink from?

☐ A bottle ☐ A cup or beaker ☐ Both

B6. If applicable, when did your child first begin drinking from a cup or a beaker?

i. ☐☐ months ii. ☐ Not applicable

B7. a) Where does your child normally eat their meals? **(Cross <u>all</u> that apply)**

☐ i) At the table ☐ iii) Walking around

☐ ii) In a highchair ☐ iv) Other (please specify) ☐

b) Is this in front of the television? ☐Yes ☐No

B8. Does your child normally eat...**(Cross <u>all</u> that apply)**

☐ i) Alone ☐ ii) With siblings

☐ iii) With parents ☐ iv) With the whole family

☐ v) Other (please specify) [ ]

B9. On average, how long does your child take to eat their main meal of the day?

☐ 0-15 minutes ☐ 30-45 minutes ☐ More than 1 hour

☐ 15-30 minutes ☐ 45 minutes-1 hour

B10. Does your child eat the same foods as the rest of the family?

☐ Usually ☐ Sometimes ☐ No

B11. Does your child have snacks in the day, between meals?

☐ No ☐ Once ☐ Twice ☐ More than twice

B12. Now that your child is 3 years of age, do you have any concerns about their eating habits?

a) ☐ Yes ☐ No

If yes
b) please specify [ ]

SECTION C - YOUR CHILD'S TEETH

C1. How many teeth does your child have now? ☐☐

C2. When do your child's teeth get brushed?

☐ Morning ☐ Morning and evening ☐ Other (please specify)

☐ Evening ☐ Never

C3. Who brushes your child's teeth?

☐ Not applicable ☐ Child ☐ Other (please specify)

☐ Parent ☐ Both

C4. What toothpaste is your child using?

☐ None ☐ Children's paste (over 3 years)

☐ Children's paste (0-3 years) ☐ Adult toothpaste

C5. a) Does your child have a drink in the last hour before bed?

☐ Yes ☐ No

If yes b) What does he/she drink? ☐ a) Water ☐ d) Squash

☐ b) Milk ☐ e) Other (please specify)

☐ c) Fruit juice

If yes c) Do you brush your child's teeth afterwards? ☐ Yes ☐ No

C6. a) Does your child drink in the night? ☐ Yes ☐ No

If yes b) What does he/she drink? ☐ a) Water ☐ d) Squash

☐ b) Milk ☐ e) Other (please specify)

☐ c) Fruit juice

C7. Do you have a family dentist? ☐ Yes ☐ No

C8. How old was your child when the dentist first looked in their mouth?

☐ Has not looked yet ☐ 18-24 months ☐ Not applicable

☐ Less than 18 months ☐ 2-3 years

C9. How often does your child visit the dentist?

☐ Every 3 months ☐ Every 4 months ☐ Every 6 months ☐ Every 12 months
☐ Not applicable ☐ Other (please specify)

C10. Has the dentist spoken to you about caring for your child's teeth?

☐ Yes ☐ No ☐ Not applicable

C11. Has the dentist spoken to you about any of the following? **(Cross all that apply)**

☐ i) Teeth brushing ☐ iii) Fluoride in toothpaste ☐ v) Fluoride in varnishes
☐ ii) Diet ☐ iv) Fluoride in water

C12. a) Did the dentist place fluoride varnish on your child's teeth?

☐ Yes ☐ No ☐ Don't know ☐ Not applicable

If yes b) How many times has this been done?

☐ Only once ☐ Twice a year ☐ 4 times a year ☐ Not applicable
☐ Once a year ☐ 3 times a year ☐ Don't know

C13. a) Has your child seen another dental specialist besides your family dentist?

☐ Yes ☐ No

If yes b) where?

☐ In the cleft team ☐ Somewhere else (specify below)
☐ At the hospital

C14. Has your child been told they have dental caries / decay?

☐ Yes ☐ No ☐ Don't know

C15. Has your child had any of the following procedures? **(Cross all that apply)**

☐ i) Filling ☐ iv) None of these **If none, go to question C16**
☐ ii) Metal Crown ☐ v) Don't know
☐ iii) Tooth removed

If yes b) Did your child have an injection in their mouth?

☐ Yes ☐ No ☐ Don't know ☐ Not applicable

If yes c) Did your child have gas and air sedation to help with the injection?

☐ Yes ☐ No ☐ Don't know ☐ Not applicable

d) Was your child asleep for the treatment?

☐ Yes ☐ No ☐ Don't know ☐ Not applicable

C16. Have you been told that your child's teeth are hypoplastic / hypomineralised (poorly formed)?

☐ Yes ☐ No ☐ Don't know

C17. Has your child ever banged their front teeth badly?

☐ Yes ☐ No ☐ Don't know

C18. Do you have any concerns about your child's teeth? **(Cross all that apply)**

☐ i) Number of teeth
☐ ii) Shape of teeth
☐ iii) Position of teeth
☐ iv) Colour of teeth
☐ v) No concerns
☐ vi) Other (please specify)

SECTION D - ADDITIONAL QUESTIONS ABOUT YOUR CHILD

D1. The following questions ask about who looks after your child (apart from yourself and your partner). **(Cross all that apply)**

Who looks after your child?	ii) How old was your child when this person / organisation regularly started looking after them?				iii) How often does this person / organisation look after your child each week?			
	Less than 6 months	Between 6 & 12 months	Between 12 & 18 months	Older than 18 months	Less than 1 day per week	1 to 2 days per week	3 to 4 days per week	More than 4 days per week
a) Child's grandparent	☐	☐	☐	☐	☐	☐	☐	☐
b) Other relative	☐	☐	☐	☐	☐	☐	☐	☐
c) Friend or neighbour	☐	☐	☐	☐	☐	☐	☐	☐
d) Paid person outside the home (e.g.child -minder)	☐	☐	☐	☐	☐	☐	☐	☐
e) Paid person inside the home (e.g. nanny /babysitter)	☐	☐	☐	☐	☐	☐	☐	☐
f) Private day nursery or creche	☐	☐	☐	☐	☐	☐	☐	☐
g) Local authority day nursery	☐	☐	☐	☐	☐	☐	☐	☐
h) Other (please specify below)	☐	☐	☐	☐	☐	☐	☐	☐

D2. a) Does your child talk using speech sounds and/or words yet?

☐ Yes ☐ No   If yes, go to question D3

If no b) does your child communicate in other ways? **(Cross all that apply)**

☐ i) Gesture / sign language   ☐ ii) Facial expression

☐ iii) Pointing or looking at things   ☐ iv) Other (please specify)

D3. The following questions are about how much of your child's speech is understood by different people. Please think about your child's speech over the **past month** when answering each question. **Cross one box for each question.**

	Always	Usually	Sometimes	Rarely	Never
a) Do you understand your child?	☐	☐	☐	☐	☐
b) Do immediate members of your family understand your child?	☐	☐	☐	☐	☐
c) Do extended members of your family understand your child?	☐	☐	☐	☐	☐
d) Do your child's friends understand your child?	☐	☐	☐	☐	☐
e) Do other acquaintances understand your child?	☐	☐	☐	☐	☐
f) Do your child's teachers/carers understand your child? (Leave blank if not applicable)	☐	☐	☐	☐	☐
g) Do strangers understand your child?	☐	☐	☐	☐	☐

D4. The following questions ask about your child's hearing

a) How would you describe your child's hearing?

☐ Normal   ☐ Very poor

☐ Slightly below normal   ☐ Not sure

☐ Poor

b) Has his/her hearing ability varied?

☐ No - normal   ☐ Yes - up and down

☐ No - always impaired   ☐ Not sure

c) Has he/she raised the sound level of the TV/radio?

☐ No ☐ Always
☐ Rarely ☐ Not sure
☐ Often

d) Has he/she responded when called in a normal voice?

☐ No ☐ Always
☐ Rarely ☐ Not sure
☐ Often

e) Has he/she misheard words when not looking at you?

☐ No ☐ Always
☐ Rarely ☐ Not sure
☐ Often

f) Has he/she turned the wrong way to a call or sound?

☐ No ☐ Always
☐ Rarely ☐ Not sure
☐ Often

g) Has he/she had difficulty hearing when spoken to face to face in a quiet room?

☐ No ☐ Always
☐ Rarely ☐ Not sure
☐ Often

h) Has he/she had difficulty hearing when with a group of people?

☐ No ☐ Always
☐ Rarely ☐ Not sure
☐ Often

i) Has he/she asked for things to be repeated?

☐ No ☐ Always
☐ Rarely ☐ Not sure
☐ Often

D5. How many times has your child had trouble with his/her ears?

☐ Not at all ☐ 2-3 times ☐ 6 or more times
☐ Once ☐ 4-5 times

D6. How many ear infections has your child had? (severe pain in ear, possibly with a temperature)

☐ 0 ☐ 2-3 ☐ Not sure
☐ 1 ☐ 4 or more

D7. How many times has your child had an earache?

☐ 0 ☐ 2-3 ☐ Not sure
☐ 1 ☐ 4 or more

D8. Has your child been involved in any other research studies?

☐ Yes ☐ No ☐ Don't know

If you answered 'No' or 'Don't know' to D8, please go to section E.

D9. a) Was/is your child involved in the study, 'Timing Of Palatal Surgery (TOPS)?

☐Yes ☐No

If yes b) When did your child have their palate repair?

☐ 6 months ☐ 9 months ☐ 12 months

c) Was/is your child involved in the study, 'Supporting Parents Of Children with a Cleft Lip (SPOCCL) study?

☐Yes ☐No

If yes d) Which group was/is your child in?

☐ 'Watch and Discover' group (children were videoed at regular intervals and met with researchers for feedback)

☐ The 'Supported Information and Advice' group

e) Was/is your child involved in another research study? (Please specify below)

SECTION E - YOUR FAMILY

E1. a) Have you had any more children in the last 18 months? ☐ Yes ☐ No

If yes b) how many? ☐ **If no, please go to E2**

c) What is the first child's date of birth? DD / MM / YY

d) What is the first child's gender? ☐ Male ☐ Female

e) What is the second child's date of birth? DD / MM / YY

f) What is the second child's gender? ☐ Male ☐ Female

E2. a) Have any of your other children (those born before or after 'study child') been born with a cleft (apart from the child in this study)?

☐ Yes ☐ No ☐ I have no other children

If yes, please give us the following information
If no, please go to E3

b) Child 1

i) Date of birth DD / MM / YY

ii) Gender
- ☐ Male
- ☐ Female

iii) What is their cleft type?
- ☐ Cleft lip
- ☐ Cleft palate
- ☐ Cleft lip and palate
- ☐ Submucous cleft palate
- ☐ Not known

iv) Is their cleft:
- ☐ Unilateral
- ☐ Bilateral
- ☐ Not known

c) Child 2

i) Date of birth DD / MM / YY

ii) Gender
- ☐ Male
- ☐ Female

iii) What is their cleft type?
- ☐ Cleft lip
- ☐ Cleft palate
- ☐ Cleft lip and palate
- ☐ Submucous cleft palate
- ☐ Not known

iv) Is their cleft:
- ☐ Unilateral
- ☐ Bilateral
- ☐ Not known

E3. a) Have **you** been diagnosed with a cleft lip or palate?

☐ No ☐ Cleft palate ☐ Submucous cleft palate

☐ Cleft lip ☐ Cleft lip and palate ☐ Don't know

If yes b) is your cleft unilateral (on one side of your mouth) or bilateral (on both sides of your mouth)?

☐ Unilateral ☐ Bilateral ☐ Don't know ☐ Not applicable

If your cleft is unilateral c) which side of your mouth is your cleft on (when someone is looking at you)?

☐ Right ☐ Left ☐ Don't know ☐ Not applicable

E4. a) Has any relative in **your family including your child's biological father and his family**, been diagnosed with a cleft lip or palate?

☐ Yes ☐ Don't know

☐ No **If no or don't know please go to E5**

b) i) Please tell us who in your family?

ii) What was their cleft type?

☐ Cleft lip
☐ Cleft palate
☐ Cleft lip and palate
☐ Submucous cleft palate
☐ Not known

iii) Was their cleft:

☐ Unilateral
☐ Bilateral
☐ Not known

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c) i) Please tell us who in your family?

ii) What was their cleft type?

☐ Cleft lip
☐ Cleft palate
☐ Cleft lip and palate
☐ Submucous cleft palate
☐ Not known

iii) Was their cleft:

☐ Unilateral
☐ Bilateral
☐ Not known

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d) i) Please tell us who in your family?

ii) What was their cleft type?

☐ Cleft lip
☐ Cleft palate
☐ Cleft lip and palate
☐ Submucous cleft palate
☐ Not known

iii) Was their cleft:

☐ Unilateral
☐ Bilateral
☐ Not known

E5. a) Have **you, the child's biological father, or any of your other children** been diagnosed with any of the following conditions? (For other children, please give their date of birth - If you have more than one child with these conditions please make a note in the comments section at the back of this questionnaire)

☐ Yes ☐ Don't know
☐ No **If no or don't know please go to E6**

	i) You	ii) Child's father	iii) Other child	iv) Other child's DOB (if applicable) in dd/mm/yy
b) Pierre Robin sequence (PRS)	☐	☐	☐	☐☐/☐☐/☐☐
c) Van der Woude syndrome	☐	☐	☐	☐☐/☐☐/☐☐
d) Treacher Collins syndrome	☐	☐	☐	☐☐/☐☐/☐☐
e) Hemifacial Microsomy / Goldenhar syndrome	☐	☐	☐	☐☐/☐☐/☐☐
f) Stickler syndrome	☐	☐	☐	☐☐/☐☐/☐☐
g) 22q 11.2 deletion syndrome (also known as Velocardiofacial syndrome, Shprintzen syndrome, DiGeorge syndrome	☐	☐	☐	☐☐/☐☐/☐☐
h) Craniosynostosis (including Crouzon syndrome, Apert syndrome, Pfeiffer syndrome, Saethre-Chotzen syndrome)	☐	☐	☐	☐☐/☐☐/☐☐
i) Cornelia de Lange syndrome	☐	☐	☐	☐☐/☐☐/☐☐
j) We are currently undergoing genetic testing at the hospital	☐	☐	☐	☐☐/☐☐/☐☐
k) Other syndrome / genetic condition (specify below)	☐	☐	☐	☐☐/☐☐/☐☐

☐

E6. a) Are any of your other children enrolled in this study? ☐ Yes ☐ No

If yes b) what is their date of birth? DD / MM / YY

If yes c) what is their gender? ☐ Male ☐ Female

E7. a) How many of your children/stepchildren live with you? ☐☐

b) How many of your siblings live with you? ☐☐

c) How many of your parents live with you? ☐☐

d) How many of your other relatives live with you? ☐☐

e) How many unrelated individuals live with you? ☐☐

E8. How long have you lived in this current household arrangement?

☐☐ years AND/OR ☐☐ months AND/OR ☐☐ weeks

E9. What is your current marital status?

☐ Single ☐ Domestic partner ☐ Married

☐ Separated ☐ Divorced ☐ Widowed

☐ Civil Union

E10. How long have you lived in this current marital arrangement?

☐☐ years AND/OR ☐☐ months AND/OR ☐☐ weeks

E11. These questions ask about your relationship with your current partner (if applicable). If not applicable please go to E12

	Agree	Agree Somewhat	Neutral	Disagree Somewhat	Disagree
a) My partner and I have a close relationship	☐	☐	☐	☐	☐
b) My partner and I have problems in our relationship	☐	☐	☐	☐	☐
c) I am very happy in my relationship	☐	☐	☐	☐	☐
d) My partner is usually understanding	☐	☐	☐	☐	☐
e) I often think about ending our relationship	☐	☐	☐	☐	☐
f) I am satisfied with my relationship with my partner	☐	☐	☐	☐	☐
g) We often disagree about important decisions	☐	☐	☐	☐	☐
h) I have been lucky in my choice of a partner	☐	☐	☐	☐	☐
i) We agree about how children should be raised	☐	☐	☐	☐	☐
j) I think my partner is satisfied with our relationship	☐	☐	☐	☐	☐

E12. How often do you do these activities with your child?

	Every day	Often	Occasionally	Hardly ever	Never
a) Bath them	☐	☐	☐	☐	☐
b) Feed them	☐	☐	☐	☐	☐
c) Sing to them	☐	☐	☐	☐	☐
d) Read to them or show them pictures	☐	☐	☐	☐	☐
e) Play with toys	☐	☐	☐	☐	☐
f) Cuddle them	☐	☐	☐	☐	☐
g) Physical play (e.g. rough and tumble or running)	☐	☐	☐	☐	☐
h) Take for a walk	☐	☐	☐	☐	☐
i) Take to soft play	☐	☐	☐	☐	☐
j) Playgroup or parent and child group	☐	☐	☐	☐	☐
k) Swimming	☐	☐	☐	☐	☐
l) Other (please specify)	☐	☐	☐	☐	☐

SECTION F - YOUR LIFESTYLE

F1. Do you currently drink alcohol? ☐ Yes ☐ No

If you answered yes to F1 go to question F2, if no go to question F3.

Please use the image below to help you answer question F2

F2. On average, how many units of alcohol do you drink **per week?**

- ☐ None
- ☐ One to two units
- ☐ Three to five units
- ☐ Five to ten units
- ☐ Ten to twenty units
- ☐ Twenty to thirty units
- ☐ More than thirty units

F3. Do you currently smoke cigarettes?

- ☐ Yes **(Go to question F4)**
- ☐ No **(Go to question F5)**

F4. On average, how many cigarettes do you currently smoke **per day?**

- ☐ Less than one per day
- ☐ One pack (15-24 per day)
- ☐ One per day
- ☐ One & ½ packs (25-34 per day)
- ☐ Two to four per day
- ☐ Two packs (35-44 per day)
- ☐ ½ a pack (5 to 14 per day)
- ☐ More than two packs per day

F5. Is your child ever exposed to passive smoke? ☐ Yes **(Go to question F6)**

☐ No **(Go to question F7)**

F6. How many hours per day is your child exposed to passive smoke?

☐ Less than one hour per day
☐ One to two hours per day
☐ Three to four hours per day
☐ More than four hours per day

F7. a) Do you currently use any drugs? ☐Yes ☐No

If yes b) how often do you use these substances? **(Cross all that apply)**

	Never	Once a year	Twice a year	Once every two months	Once a month	Twice a month	Once a week or more
i) Cannabis	☐	☐	☐	☐	☐	☐	☐
ii) Cocaine	☐	☐	☐	☐	☐	☐	☐
iii) Ecstasy	☐	☐	☐	☐	☐	☐	☐
iv) Amphetamine	☐	☐	☐	☐	☐	☐	☐
v) Heroin	☐	☐	☐	☐	☐	☐	☐
vi) Other (specify below)	☐	☐	☐	☐	☐	☐	☐

F8. During a typical week, how many minutes/times on average do you do the following types of exercise?

i) Vigorous exercise (breathing hard, heart beats rapidly).
For example: running, aerobics, martial arts, fast swimming, or a team sport such as football or hockey ☐☐☐ minutes per week

ii) Moderate exercise (heart rate increases slightly, but is not exhausting).
For example: fast walking or gentle cycling ☐☐☐ minutes per week

iii) Muscle strengthening activities
For example: lifting weights, push-ups and sit-ups, heavy gardening or yoga ☐☐ times per week

SECTION G - YOUR WELLBEING

G1. How many close friends do you have (other than your partner, if applicable)?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 or more

G2. Overall, how would you rate your relationships with your close friends?

☐ Poor ☐ Fair ☐ Good ☐ Excellent

G 3. In the last year, have you experienced a period of acute stress or an emotional event which had an influence on your state of mind?
(Please cross <u>all</u> boxes that apply to you)

☐ i) Death of a partner

☐ ii) Divorce

☐ iii) Marital separation

☐ iv) Prison sentence

☐ v) Death of a parent or close family member

☐ vi) Personal injury or illness

☐ vii) Marriage

☐ viii) Being sacked or laid off from work

☐ ix) Marital reconciliation

☐ x) Retirement

☐ xi) Change in health of family member

☐ xii) Pregnancy

☐ xiii) Sex difficulties

☐ xiv) Gaining a new family member

☐ xv) Business readjustment

☐ xvi) Change in financial state

☐ xvii) Death of a close friend

☐ xviii) Change to a different line of work

G3 continued...

☐ xix) Change in number of arguments with spouse

☐ xx) Setting up a mortgage

☐ xxi) Foreclosure of mortgage or loan

☐ xxii) Change in responsibilities at work

☐ xxiii) Son or daughter leaving home

☐ xxiv) Trouble with in-laws

☐ xxv) Outstanding personal achievement

☐ xxvi) Partner begins or stops work

☐ xxvii) Begin or end school/higher education

☐ xxviii) Change in living conditions

☐ xxix) Change in personal habits

☐ xxx) Trouble with your boss at work

☐ xxxi) Change in work hours or conditions

☐ xxxii) Moving house

☐ xxxiii) Change in schools/higher education

☐ xxxiv) Change in hobbies

☐ xxxv) Change in church activities

☐ xxxvi) Change in social activities

☐ xxxvii) Getting a small loan

☐ xxxviii) Change in sleeping habits

☐ xxxix) Change in the number of family get-togethers

☐ xl) Change in eating habits

☐ xli) Holiday

☐ xlii) Christmas

☐ xliii) Minor breaches of the law

G4. Families sometimes have special concerns or difficulties because of their child's health. Below there is a list of things that might be a problem for **you.**

In the past **one month, as a result of your child's health**, how much of a problem have you had with...

	Never	Almost never	Some- times	Often	Almost always
a) I feel tired during the day	☐	☐	☐	☐	☐
b) I feel tired when I wake up in the morning	☐	☐	☐	☐	☐
c) I feel too tired to do the things I like to do	☐	☐	☐	☐	☐
d) I get headaches	☐	☐	☐	☐	☐
e) I feel physically weak	☐	☐	☐	☐	☐
f) I feel sick to my stomach	☐	☐	☐	☐	☐
g) I feel anxious	☐	☐	☐	☐	☐
h) I feel sad	☐	☐	☐	☐	☐
i) I feel angry	☐	☐	☐	☐	☐
j) I feel frustrated	☐	☐	☐	☐	☐
k) I feel helpless or hopeless	☐	☐	☐	☐	☐
l) I feel isolated from others	☐	☐	☐	☐	☐
m) I have trouble getting support from others	☐	☐	☐	☐	☐
n) It is hard to find time for social activities	☐	☐	☐	☐	☐
o) I do not have enough energy for social activities	☐	☐	☐	☐	☐

G4 continued...

	Never	Almost never	Some-times	Often	Almost always
p) It is hard for me to keep my attention on things	☐	☐	☐	☐	☐
q) It is hard for me to remember what people tell me	☐	☐	☐	☐	☐
r) It is hard for me to remember what I just heard	☐	☐	☐	☐	☐
s) It is hard for me to think quickly	☐	☐	☐	☐	☐
t) I have trouble remembering what I was just thinking	☐	☐	☐	☐	☐
u) I feel that others do not understand my family's situation	☐	☐	☐	☐	☐
v) It is hard for me to talk about my child's health with others	☐	☐	☐	☐	☐
w) It is hard for me to tell doctors and nurses how I feel	☐	☐	☐	☐	☐
x) I worry about whether or not my child's medical treatments are working	☐	☐	☐	☐	☐
y) I worry about the side effects of my child's medications/medical treatments	☐	☐	☐	☐	☐
z) I worry about how others will react to my child's condition	☐	☐	☐	☐	☐
aa) I worry about how my child's illness is affecting other family members	☐	☐	☐	☐	☐
bb) I worry about my child's future	☐	☐	☐	☐	☐

G5. Below is a list of things that might be a problem for your **family**.

In the past **one month, as a result of your child's health**, how much of a problem has **your family** had with...

	Never	Almost never	Some-times	Often	Almost Always
a) Family activities taking more time and effort	☐	☐	☐	☐	☐
b) Difficulty finding time to finish household tasks	☐	☐	☐	☐	☐
c) Feeling too tired to finish household tasks	☐	☐	☐	☐	☐
d) Lack of communication between family members	☐	☐	☐	☐	☐
e) Conflicts between family members	☐	☐	☐	☐	☐
f) Difficulty making decisions together as a family	☐	☐	☐	☐	☐
g) Difficulty solving family problems together	☐	☐	☐	☐	☐
h) Stress or tension between family members	☐	☐	☐	☐	☐

G6. Please answer the following questions telling us how happy you are with the care **you, your child, and your family** have received at the hospital from the staff.

Please cross N/A (not applicable) if the item does not apply to you.

How happy are you with...

	Never happy	Some-times	Often happy	Almost always	Always happy	N/A
a) How much information was provided to you about your child's diagnosis?	☐	☐	☐	☐	☐	☐
b) How much information was provided to you about the treatment and course of your child's health condition?	☐	☐	☐	☐	☐	☐
c) How much information was provided to you about the side effects of your child's treatment?	☐	☐	☐	☐	☐	☐

G6 continued...

How happy are you with...

	Never happy	Some-times	Often happy	Almost always	Always happy	N/A
d) How soon information was given to you about your child's test results?	☐	☐	☐	☐	☐	☐
e) How often you are updated about your child's health?	☐	☐	☐	☐	☐	☐
f) The sensitivity shown to you and your family during your child's treatment?	☐	☐	☐	☐	☐	☐
g) The willingness to answer questions that you and your family may have?	☐	☐	☐	☐	☐	☐
h) The effort to include your family in discussion of your child's care and other information about your child's health condition?	☐	☐	☐	☐	☐	☐
i) How much time the staff give you to ask any questions you may have had about your child's health condition and treatment?	☐	☐	☐	☐	☐	☐
j) How well the staff explain your child's health condition and treatment to **your child** in a way that she/he can understand?	☐	☐	☐	☐	☐	☐
k) The time taken to explain your child's health condition and treatment to **you** in a way that you could understand?	☐	☐	☐	☐	☐	☐
l) How well the staff listen to you and your concerns?	☐	☐	☐	☐	☐	☐
m) The preparation provided for **you** about what to expect during tests and procedures?	☐	☐	☐	☐	☐	☐

G6 continued...

How happy are you with:	Never happy	Some-times	Often happy	Almost always	Always happy	N/A
n) The preparation provided for **your child** about what to expect during tests and procedures?	☐	☐	☐	☐	☐	☐
o) How well the staff respond to your child's needs?	☐	☐	☐	☐	☐	☐
p) Efforts to keep your child comfortable and as pain-free as possible?	☐	☐	☐	☐	☐	☐
q) How much time the staff take to help you with your child coming back home after hospitalisation?	☐	☐	☐	☐	☐	☐
r) The amount of time given to your child to play, talk about her/his feelings, and any questions she/he may have?	☐	☐	☐	☐	☐	☐
s) The amount of time spent helping your child with going back to school after hospitalisation?	☐	☐	☐	☐	☐	☐
t) The amount of time spent attending to **your child's** emotional needs?	☐	☐	☐	☐	☐	☐
u) The amount of time spent attending to **your** emotional needs?	☐	☐	☐	☐	☐	☐
v) The overall care your child is receiving?	☐	☐	☐	☐	☐	☐
w) How friendly and helpful the staff are?	☐	☐	☐	☐	☐	☐
x) The way your child is treated at the hospital?	☐	☐	☐	☐	☐	☐

We are asking these questions to help us understand the challenges families may experience. This will allow us to make recommendations about support that could be made available.

G7. These questions ask you about your feelings and thoughts **during the last month.**

	Never	Almost never	Some-times	Fairly often	Very often
a) How often have you been upset because of something that happened unexpectedly?	☐	☐	☐	☐	☐
b) How often have you felt that you were unable to control the important things in your life?	☐	☐	☐	☐	☐
c) How often have you felt nervous and "stressed"?	☐	☐	☐	☐	☐
d) How often have you felt confident about your ability to handle your personal problems?	☐	☐	☐	☐	☐
e) How often have you felt that things were going your way?	☐	☐	☐	☐	☐
f) How often have you found that you could not cope with all the things that you had to do?	☐	☐	☐	☐	☐
g) How often have you been able to control irritations in your life?	☐	☐	☐	☐	☐
h) How often have you felt that you were on top of things?	☐	☐	☐	☐	☐
i) How often have you been angered because of things that were outside of your control?	☐	☐	☐	☐	☐
j) How often have you felt difficulties were piling up so high that you could not overcome them?	☐	☐	☐	☐	☐

G8. These questions ask you about your feelings and thoughts **during the last month.**

a) I feel tense or 'wound up'

☐ Most of the time
☐ A lot of the time
☐ From time to time, occasionally
☐ Not at all

b) I still enjoy the things I used to enjoy

☐ Definitely as much
☐ Not quite so much
☐ Only a little
☐ Hardly at all

c) I get a sort of frightened feeling as if something awful is about to happen

☐ Very definitely and quite badly
☐ Yes, but not too badly
☐ A little, but it doesn't worry me
☐ Not at all

d) I can laugh and see the funny side of things

☐ As much as I always could
☐ Not quite so much now
☐ Definitely not so much now
☐ Not at all

e) Worrying thoughts go through my mind

☐ A great deal of the time
☐ A lot of the time
☐ From time to time, but not too often
☐ Only occasionally

f) I feel cheerful

☐ Not at all
☐ Not often
☐ Sometimes
☐ Most of the time

g) I can sit at ease and feel relaxed

☐ Definitely
☐ Usually
☐ Not often
☐ Not at all

h) I feel as if I am slowed down

☐ Nearly all the time
☐ Very often
☐ Sometimes
☐ Not at all

G8 continued...

i) I get a sort of frightened feeling like 'butterflies' in the stomach

- ☐ Not at all
- ☐ Occasionally
- ☐ Quite often
- ☐ Very often

j) I have lost interest in my appearance

- ☐ Definitely
- ☐ I don't take as much care as I should
- ☐ I may not take quite as much care
- ☐ I take just as much care as ever

k) I feel restless as I have to be on the move

- ☐ Very much indeed
- ☐ Quite a lot
- ☐ Not very much
- ☐ Not at all

l) I look forward with enjoyment to things

- ☐ As much as I ever did
- ☐ Rather less than I used to
- ☐ Definitely less than I used to
- ☐ Hardly at all

m) I get sudden feelings of panic

- ☐ Very often indeed
- ☐ Quite often
- ☐ Not very often
- ☐ Not at all

n) I can enjoy a good book or radio or TV Programme

- ☐ Often
- ☐ Sometimes
- ☐ Not often
- ☐ Very seldom

The following questions ask about activities children may do. Your child may have already done some of the activities described here, and there may be some your child has not yet begun doing. For each item, please cross the box that indicates whether your child is doing the activity, or not yet.

G9.

	Yes	**Some-times**	**Not yet**
a) If you ask your child to point to his/her nose, eyes, hair, etc. can he/she correctly point to at least seven body parts?	☐	☐	☐
b) Does your child make sentences that are three or four words long?	☐	☐	☐
c) If you ask your child to 'put the book *on* the table' and 'put the shoe *under* the chair,' can he/she carry out both of these directions correctly?	☐	☐	☐
d) When looking at a picture book, can your child tell you what is happening in the picture (eg. 'running,' 'eating,' or 'crying')?	☐	☐	☐
e) Can your child consistently move a coat zip up and down if you ask them to?	☐	☐	☐
f) When you ask, 'What is your name?' does your child say both his/her first and last names?	☐	☐	☐

G10.

	Yes	**Some-times**	**Not yet**
a) Without holding onto anything for support, can your child kick a ball by swinging his/her leg forward?	☐	☐	☐
b) Can your child jump with both feet leaving the floor at the same time?	☐	☐	☐
c) Can your child walk up stairs, using only one foot on each stair? (They may hold onto the railing or wall)	☐	☐	☐
d) Can your child stand on one foot for about one second without holding onto anything?	☐	☐	☐
e) While standing, can your child throw a ball *overhand* by raising his/her arm shoulder height and throwing the ball forward?	☐	☐	☐
f) Can your child jump **forward** at least 6 inches with both feet leaving the ground at the same time?	☐	☐	☐

G11.	Yes	Some-times	Not yet
a) Can your child copy a drawing of a single line in a vertical direction?	☐	☐	☐
b) Can your child string small items such as beads or pasta onto a string or shoelace?	☐	☐	☐
c) Can your child copy a drawing of a circle?	☐	☐	☐
d) Can your child copy a drawing of a single line in a horizontal direction?	☐	☐	☐
e) Can your child try to cut paper with child-safe scissors?	☐	☐	☐
f) When drawing, can your child hold a pencil, crayon, or pen between her fingers and thumb like an adult?	☐	☐	☐

G12.	Yes	Some-times	Not yet
a) Can your child copy you if you line up four objects in a row?	☐	☐	☐
b) If your child wants something he/she cannot reach, does he/she find a chair or box to stand on to reach it?	☐	☐	☐
c) If you point to a figure of a person and ask your child, 'What is this?' does your child say a word that means a person or something similar? (eg. 'boy,' 'daddy')	☐	☐	☐
d) If you say two numbers in a row, can he/she repeat these two numbers in the same order?	☐	☐	☐
e) If you show your child how to make a bridge with blocks, does your child copy you by making one like it?	☐	☐	☐
f) If you say three numbers in a row, can your child repeat these three numbers in the same order?	☐	☐	☐

G13.

	Yes	Some-times	Not yet
a) Does your child use a spoon to feed him/herself with little spilling?	☐	☐	☐
b) Can your child push a little toy on wheels, steering it around objects and backing it out of corners?	☐	☐	☐
c) When your child is looking in the mirror and you ask, 'Who is in the mirror?' does he/she say either 'me' or his/her own name?	☐	☐	☐
d) Can your child put on a coat, jacket, or shirt by him/herself?	☐	☐	☐
e) If you ask your child 'Are you a girl or a boy?' does your child answer correctly?	☐	☐	☐
f) Does your child take turns by waiting while another child or adult takes a turn?	☐	☐	☐

G14. Do you think your child talks like other children his / her age?

a) ☐Yes ☐No

If no
b) please explain

G15. These questions ask about your child's development. Please cross the box which best describes your child's behaviour. In addition, please cross the final box if this behaviour is a concern to you.

	Most of the time	Some-times	Rarely or never	Cross if this is a concern
a) Does your child look at you when you talk to him/her?	☐	☐	☐	☐
b) Does you child like to be hugged or cuddled?	☐	☐	☐	☐
c) Does your child talk and/or play with adults he/she knows well?	☐	☐	☐	☐
d) Does your child cling to you more than you expect?	☐	☐	☐	☐
e) When upset, can your child calm down within fifteen minutes?	☐	☐	☐	☐
f) Does your child seem too friendly with strangers?	☐	☐	☐	☐
g) Can your child settle him/herself down after periods of exciting activity?	☐	☐	☐	☐
h) Can your child move from one activity to the next with little difficulty, such as from playtime to mealtime?	☐	☐	☐	☐
i) Does your child seem happy?	☐	☐	☐	☐
j) Is your child interested in things around him/her, such as people, toys, and foods?	☐	☐	☐	☐
k) Does your child do what you ask him/her to do?	☐	☐	☐	☐
l) Does your child seem more active than other children his/her age?	☐	☐	☐	☐
m) Can your child stay with activities he/she enjoys for at least five minutes (not including watching television)?	☐	☐	☐	☐
n) Do you and your child enjoy mealtimes together?	☐	☐	☐	☐

G15. Continued

	Most of the time	Some-times	Rarely or never	Cross if this is a concern
o) Does your child have eating problems, such as stuffing foods, vomiting, or eating nonfood items?	☐	☐	☐	☐
p) Does your child sleep at least 8 hours in a 24-hour period?	☐	☐	☐	☐
q) Does your child use words to tell you what he wants or needs?	☐	☐	☐	☐
r) Does your child follow routine directions?	☐	☐	☐	☐
s) Does your child cry, scream, or have tantrums for long periods of time?	☐	☐	☐	☐
t) Does your child check to make sure you are near when exploring new places, such as a park or a friend's home?	☐	☐	☐	☐
u) Does your child do things over and over and can't seem to stop? (eg. rocking, hand flapping or spinning)	☐	☐	☐	☐
v) Does your child hurt him/herself on purpose?	☐	☐	☐	☐
w) Does your child stay away from dangerous things, such as fire and moving cars?	☐	☐	☐	☐
x) Does your child destroy or damage things on purpose?	☐	☐	☐	☐
y) Does your child use words to describe his/her feelings and the feelings of others, such as, 'I'm happy,' 'I don't like that,' or 'She's sad'?	☐	☐	☐	☐
z) Can your child name a friend?	☐	☐	☐	☐
aa) Do *other* children like to play with your child?	☐	☐	☐	☐
bb) Does *your child* like to play with other children?	☐	☐	☐	☐

G15. Continued

	Most of the time	Some-times	Rarely or never	Cross if this is a concern
cc) Does your child try to hurt other children, adults, or animals (eg. by kicking or biting)?	☐	☐	☐	☐
dd) Does your child show an interest in or knowledge of adult sexual language and activity?	☐	☐	☐	☐
ee) Has anyone expressed concerns about your child's behaviour? If you cross 'sometimes' or 'most of the time', please specify in the box below	☐	☐	☐	☐

G16. a) Do you have concerns about your child's eating or sleeping, or toilet habits?

☐Yes ☐No

If yes b) please explain

G17. a) Is there anything that worries you about your child? ☐Yes ☐No

If yes b) please explain

G18. What things do you enjoy most about your child?

G19. a) How noticeable do you think your child's cleft is to other people?

- ☐ Not at all
- ☐ Quite noticeable
- ☐ A little
- ☐ Very noticeable

b) These questions ask you about **your** feelings about your child's cleft. To what extent are each of these statements true of your feelings over the last **six months?**

	Never	Almost never	Some-times	Often	Almost always
i) I feel that the cleft is dominating my experience of bringing up my child	☐	☐	☐	☐	☐
ii) I feel that it is my fault that my child was born with a cleft	☐	☐	☐	☐	☐
iii) I struggle to come to terms with my child's cleft	☐	☐	☐	☐	☐
iv) I worry that I am unable to care for my child because of the cleft	☐	☐	☐	☐	☐
v) I worry about other health problems my child may have	☐	☐	☐	☐	☐
vi) I worry that the cleft is affecting my relationship with my child	☐	☐	☐	☐	☐
vii) I worry that the cleft is affecting my child's relationship with other people	☐	☐	☐	☐	☐
viii) I worry about my child's future cleft treatment	☐	☐	☐	☐	☐
ix) I feel optimistic about my child's future	☐	☐	☐	☐	☐
x) I feel that there are positives to having a child with a cleft (please specify below)	☐	☐	☐	☐	☐

The Cleft Lip and Palate Association (CLAPA) is a UK charity which provides support to families affected by cleft lip/palate. CLAPA are separate from your cleft team.

G20. Since your child's cleft was diagnosed, have you received any support from CLAPA? ☐ Yes ☐ No

If no, go to section H

For more information about CLAPA please go to the website; www.clapa.com, or contact them by telephone on 020 7833 4883

G21. What type of support have you received from CLAPA? **(Cross all that apply)**

☐ a) Information about cleft lip and palate
☐ b) Information about treatment
☐ c) Feeding bottles
☐ d) Emotional support
☐ e) Other (specify below)

G22. Do you still receive support from CLAPA?

☐ Yes, frequently ☐ Yes, occasionally ☐ No

G23. How often have you been satisfied with the support you have received from CLAPA?

☐ Never ☐ Almost never ☐ Sometimes ☐ Often
☐ Almost always ☐ Always

G24. Are you currently an active CLAPA volunteer? ☐ Yes ☐ No

SECTION H - ADDITIONAL QUESTIONS FOR THE MOTHER

H1. a) Does the child's biological father currently live with you? ☐Yes ☐No

If no b) how old was the child when the biological father left the home?

i)

Years		Months		Weeks	

ii) Biological father left the home before child was born ☐

Please go to section Z

SECTION Z

Z1. This questionnaire was completed by:

a) Child's biological mother ☐

b) Someone else (please cross box and describe) ☐ [ ]

Z2. Do you live in the same house as the child? ☐ Yes ☐ No

Z3. On what date did you complete this questionnaire?

DD / MM / YYYY

Z4. Please give **your** date of birth

DD / MM / YYYY

Z5. Please give **your child's** date of birth

DD / MM / YYYY

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE.

Please use this space for any additional comments you would like to make:

When completed please send this back in the freepost brown envelope to:

The Cleft Collective
University of Bristol
Oakfield House
Oakfield Grove
Bristol, BS8 2BN

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