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

ID LABEL

For Birth Cohort

You and Your Child at 5 Years

Mother's questionnaire

This questionnaire is for the child's mother.

University of BRISTOL

UWE BRISTOL University of the West of England

THE SCAR FREE FOUNDATION

VTCT WORLD CLASS QUALIFICATIONS

October 2020 - Version 1
(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 eight sections:

A. **Your Child's Health** - This section asks questions related to the health of your child
B. **Your Child's Teeth** - This section asks questions about your child's teeth and dentist
C. **Additional Questions About Your Child -** This section asks additional questions not covered in any other section including childcare, sleep position and hearing
D. **Work and Education -** This section asks for information including your educational achievements and your current employment status
E. **Health and Illness** - This section asks questions about your health history
F. **Your Lifestyle** - This section asks questions about your diet, alcohol use, cigarette smoking and exercise
G. **Your Wellbeing** - This section asks about how you have been feeling recently
H. **Your Family** - The last section asks about where you live, your partner and your other children (if applicable)

Please try to answer all of the questions, 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

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 cleft 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 <u>all</u> 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 <u>all</u> 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
- ☐ b) Ears
- ☐ c) Cheekbones
- ☐ d) Jaw
- ☐ e) Tongue
- ☐ f) Hands
- ☐ g) Feet
- ☐ h) Spine
- ☐ i) Other developmental condition (please specify)
- ☐ 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) 22q11.2 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 - YOUR CHILD'S TEETH

B1. How many teeth does your child have now? ☐☐

B2. When do your child's teeth get brushed?

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

☐ Evening ☐ Never ☐

B3. Who brushes your child's teeth?

☐ Not applicable ☐ Child ☐ Other (please specify)

☐ Parent ☐ Both ☐

B4. What toothpaste is your child using?

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

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

B5. a) Does your child have a drink in the last hour before bed?

☐ Yes ☐ No

If yes b) What does he/she drink? **(Cross all that apply)**

☐ i) Water ☐ iv) Squash

☐ ii) Milk ☐ v) Other (please specify)

☐ iii) Fruit juice ☐

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

B6. a) Does your child drink in the night? ☐ Yes ☐ No

If yes b) What does he/she drink? **(Cross all that apply)**

☐ i) Water ☐ iv) Squash

☐ ii) Milk ☐ v) Other (please specify)

☐ iii) Fruit juice ☐

B7. Do you have a family dentist? ☐ Yes ☐ No

B8. How old was your child when the dentist first looked in their mouth?

☐ Has not looked yet ☐ 18-24 months ☐ 3-4 years ☐ Not applicable

☐ Less than 18 months ☐ 2-3 years ☐ 4-5 years

B9. 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) _____

B10. Has the dentist spoken to you about caring for your child's teeth?

☐ Yes ☐ No ☐ Not applicable

B11. Has the dentist spoken to you about any of the following? **(Cross all that apply)**

☐ i) Tooth brushing ☐ iii) Fluoride in toothpaste ☐ v) Fluoride in varnishes

☐ ii) Diet ☐ iv) Fluoride in water ☐ vi) No

B12. a) Has the dentist ever put 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

B13. a) Has your child seen another dental specialist besides your family dentist?

☐ Yes ☐ No

If yes b) Where? **(Cross all that apply)**

☐ i) In the cleft team ☐ iii) Somewhere else (specify below)

☐ ii) At the hospital _____

B14. Has your child been told they have dental caries / decay?

☐ Yes ☐ No ☐ Don't know

B15. a) Has your child had any of the following procedures? **(Cross all that apply)**

☐ i) Filling ☐ iv) None of these **If none, go to question B16**

☐ 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

If yes d) Was your child asleep for the treatment?

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

B16. Have you been told that your child's teeth are hypoplastic / hypomineralised (poorly formed)?

☐ Yes ☐ No ☐ Don't know

B17. Has your child ever banged their front teeth badly?

☐ Yes ☐ No ☐ Don't know

B18. Do you have any concerns about your child's teeth? **(Cross <u>all</u> 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 C - ADDITIONAL QUESTIONS ABOUT YOUR CHILD

We are interested to know who is involved in caring for your child to see whether this has an impact on children's overall development.

C1. Apart from yourself and your partner, who regularly looked after your child from when they were **3 years old until they started school?**

a) ☐ No one else looked after my child

Who looked after your child?	i) How often did this person / organisation look after your child each week?			
	Less than 1 day per week	1 to 2 days per week	3 to 4 days per week	More than 4 days per week
b) Child's grandparent	☐	☐	☐	☐
c) Other relative	☐	☐	☐	☐
d) Friend or neighbour	☐	☐	☐	☐
e) Paid person outside the home (e.g.child -minder)	☐	☐	☐	☐
f) Paid person inside the home (e.g. nanny / babysitter)	☐	☐	☐	☐
g) Private day nursery or creche	☐	☐	☐	☐
h) Local authority day nursery	☐	☐	☐	☐
i) Pre-School or equivalent	☐	☐	☐	☐
j) Other (please specify)	☐	☐	☐	☐

The following questions ask about who regularly looks after your child since they started school **(Cross all that apply)**

C2. Apart from yourself and your partner, who regularly looks after your child **on school days?**

a) ☐ No one else looks after my child

Who looks after your child?	i) How often does this person / organisation look after your child each week?			
	Less than 1 day per week	1 to 2 days per week	3 to 4 days per week	More than 4 days per week
b) Child's grandparent	☐	☐	☐	☐
c) Other relative	☐	☐	☐	☐
d) Friend or neighbour	☐	☐	☐	☐
e) Paid person outside the home (e.g.child -minder)	☐	☐	☐	☐
f) Paid person inside the home (e.g. nanny /babysitter)	☐	☐	☐	☐
g) After school club	☐	☐	☐	☐
h) Other (please specify)	☐	☐	☐	☐

C3. What ways does your child communicate? **(Cross all that apply)**

☐ i) Speech

☐ ii) Gesture / sign language

☐ iii) Facial expression

☐ iv) Pointing or looking at things

☐ v) Other (please specify)

C4. 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?	☐	☐	☐	☐	☐

C5. 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

C6. In their lifetime 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

C7. In their lifetime how many ear infections (severe pain in ear, possibly with a temperature) has your child had?

☐ 0 ☐ 2-3 ☐ Not sure
☐ 1 ☐ 4 or more

C8. How many times has your child had an earache?

☐ 0 ☐ 2-3 ☐ Not sure
☐ 1 ☐ 4 or more

SECTION D - WORK AND EDUCATION

You may have answered some of these questions before. We are asking them again as we are interested to know if anything has changed since the last questionnaire. We are trying to see if there are links between these factors and children's health and wellbeing.

D1. What is the highest educational qualification you have obtained? **(Cross <u>one</u> box only)**

- ☐ One or more O Levels/CSEs/GCEs (any grades)
- ☐ Five or more O Levels/CSEs (grade 1)/GCSEs (grades A*-C)/School Certificate
- ☐ One or more A Levels/AS Levels
- ☐ Two or more A Levels/Four or more AS Levels/Higher School Certificate
- ☐ NVQ Level 1/Foundation GNVQ
- ☐ NVQ Level 2/Intermediate GNVQ
- ☐ NVQ Level 3/Advanced GNVQ
- ☐ NVQ Levels 4-5/HNC/HND
- ☐ First degree (e.g. BA/BSc)
- ☐ Higher degree (e.g. MA, PhD, postgraduate PGCE)
- ☐ Other qualifications (e.g. City and Guilds, RSA/OCR, BTEC/Edexcel)
- ☐ Overseas qualifications (please specify) ____
- ☐ No qualifications
- ☐ Don't know
- ☐ Other (please specifiy) ____

D2. What is your current employment status? **(Cross <u>one</u> box only)**

- ☐ Student
- ☐ Homemaker
- ☐ Intern/apprentice
- ☐ Military Service
- ☐ Unemployed/laid off
- ☐ Rehabilitation/disabled
- ☐ Employed in public sector
- ☐ Employed in private sector
- ☐ Self-employed
- ☐ Other (please specify below)

____

D3. What is your current/most recent occupation? **(Cross <u>one</u> box only).** See below for examples of occupation types.

- ☐ Professional/executive
- ☐ Small business, proprietor, sales
- ☐ Clerical/administrative
- ☐ Skilled worker
- ☐ Semi-skilled worker
- ☐ Unskilled worker
- ☐ Student/school pupil
- ☐ Homemaker
- ☐ Volunteer worker
- ☐ Other (please specify below)

EXAMPLES OF OCCUPATION TYPES

<u>Professional/Executive:</u> An expert in the field in which you work, with education beyond an undergraduate degree (e.g. masters degree or doctorate) OR an individual with a top level position in a business setting with over 100 employees, e.g. lawyer, doctor.

<u>Small business, proprietor, sales:</u> Working in a business with under 100 employees.

<u>Clerical/administrative:</u> Working in an office and performing day-to-day business-related tasks such as organising meetings, typing, writing proposals, and budgeting.

<u>Skilled worker:</u> Any worker who has some special knowledge in his/her work and who has usually attended a college, university, or technical school and may have a diploma, or undergraduate degree. Or a skilled worker who may have learned their skills on the job, e.g. teacher, nurse, plumber, electrician.

<u>Semi-skilled worker:</u> A semi-skilled worker who has received little specialised training to do their work.

<u>Unskilled worker:</u> An unskilled worker who has received no special training to do their work.

D4. What is your current/most recent job title?

D5. How long have you worked/did you work in your current/most recent job?

☐☐ Years ☐☐ Months

D6. a) In the last year, have you been absent from work for more than two weeks in a row (apart from maternity leave)?

☐ Yes ☐ No

b) **If yes**, what was the reason for your absence? **(Cross <u>one</u> box only)**

Medical leave ☐ Leave of absence ☐

Child was ill ☐ Other (please specify below) ☐

D7. On average, how many hours do you currently work per week? ☐☐ hours per week

D8. What are your current working hours? **(Cross <u>one</u> box only)**

☐ Permanent day work ☐ Permanent evening work

☐ Permanent night work ☐ Shift work or shift rotations

☐ No set times (e.g. temporary employment) ☐ Other (please specify)

D9. How do the following statements describe your current work situation?

	Disagree	Disagree Mostly	Agree Mostly	Agree
a) I do physically heavy work	☐	☐	☐	☐
b) My work is very stressful	☐	☐	☐	☐
c) I learn a lot at work	☐	☐	☐	☐
d) My work is very monotonous	☐	☐	☐	☐
e) My work demands a lot of me	☐	☐	☐	☐
f) I am able to decide how my work is carried out	☐	☐	☐	☐
g) There is a good team spirit at my place of work	☐	☐	☐	☐
h) I enjoy my work	☐	☐	☐	☐

D10. **This table shows income in weekly, monthly and annual amounts.** Which of the amounts on this list represents **YOUR INDIVIDUAL** total income from all jobs, tax credits, benefits and other sources **after tax** when added together? (**Cross <u>one</u> box only)**

Weekly Income after Tax	**Monthly Income after Tax**	**Annual Income after Tax**	
Less than £25	Less than £108	Less than £1,299	☐
£25 - £39	£109 - £175	£1,300 - £2,099	☐
£40 - £59	£176 - £259	£2,100 - £3,099	☐
£60 - £79	£260 - £350	£3,100 - £4,199	☐
£80 - £99	£351 - £433	£4,200 - £5,199	☐
£100 - £124	£434 - £542	£5,200 - £6,499	☐
£125 - £149	£543 - £650	£6,500 - £7,799	☐
£150 - £179	£651 - £775	£7,800 - £9,299	☐
£180 - £209	£776 - £917	£9,300 - £10,999	☐
£210 - £259	£918 - £1,125	£11,000 - £13,499	☐
£260 - £299	£1,126 - £1,333	£13,500 - £15,999	☐
£300 - £379	£1,334 - £1,667	£16,000 - £19,999	☐
£380 - £479	£1,668 - £2,083	£20,000 - £24,999	☐
£480 - £577	£2,084 - £2,500	£25,000 - £29,999	☐
£578 - £769	£2,501 - £3,333	£30,000 - £39,999	☐
£770 - £962	£3,334 - £4,167	£40,000 - £49,999	☐
£963 - £1,154	£4,168 - £5,000	£50,000 - £59,999	☐
£1,155 - £1,346	£5,001 - £5,833	£60,000 - £69,999	☐
£1,347 - £1,538	£5,834 - £6,667	£70,000 - £79,999	☐
£1,539 or more	£6,668 or more	£80,000 or more	☐

D11. Which of these credits/allowances/benefits do **YOU** receive as an individual? **(Cross all that apply)**

- ☐ a) Child benefit
- ☐ b) Child tax credit
- ☐ c) Working tax credit
- ☐ d) Income support
- ☐ e) Disability living allowance/personal independence payment (PIP)
- ☐ f) Income tested job seeker's allowance
- ☐ g) Housing benefit/rent rebate/council tax benefit/council tax reduction
- ☐ h) Incapacity benefits/employment and support allowance (ESA)
- ☐ i) Pension credit
- ☐ j) Carer's allowance
- ☐ k) Universal Credit
- ☐ l) None
- ☐ m) Don't know
- ☐ n) Other (please specify below)

D12. Approximately how much of **YOUR** total individual income comes from benefits?

- ☐ None
- ☐ A small amount (less than 25%)
- ☐ A fair amount (between 25% and 50%)
- ☐ The majority (50% or more)

SECTION E - HEALTH AND ILLNESS

E1. Have you been diagnosed by a medical professional with any of the following medical conditions? **(Cross <u>all</u> that apply)**

- ☐ 0) None
- ☐ i) Epilepsy or seizures
- ☐ ii) High blood pressure
- ☐ iii) Diabetes
- ☐ iv) Heart Disease
- ☐ v) Arthritis
- ☐ vi) Thyroid condition
- ☐ vii) Hepatitis
- ☐ viii) Lupus
- ☐ ix) Severe acne
- ☐ x) Asthma
- ☐ xi) Allergies
- ☐ xii) Severe headaches
- ☐ xiii) Chronic ear infections
- ☐ xiv) Other medical condition (please specify below)

E2. Have you been diagnosed by a medical professional with any of the following types of cancer? **(Cross <u>all</u> that apply)**

- ☐ 0) None
- ☐ i) Breast
- ☐ ii) Cervical
- ☐ iii) Colon and/or rectum
- ☐ iv) Leukaemia
- ☐ v) Lung
- ☐ vi) Prostate
- ☐ vii) Skin
- ☐ viii) Testicular
- ☐ ix) Thyroid
- ☐ x) Uterus
- ☐ xi) Other type of cancer (please specify below)

E3. Have you been diagnosed by a medical professional with any of the following specific health conditions? **(Cross <u>all</u> that apply)**

- ☐ 0) None
- ☐ i) Heart defect
- ☐ ii) Short-sightedness
- ☐ iii) Learning disability
- ☐ iv) Other congenital defect (other than cleft)
- ☐ v) Genetic disorder
- ☐ vi) Hearing loss or impairment

vii) **If yes to vi), please tell us about the type of hearing loss:**

- ☐ Temporary (conductive)
- ☐ Permanent (sensorineural)
- ☐ Don't know

viii) **If this hearing loss is permanent, do you use hearing aids?**

☐ Yes ☐ No ☐ Don't know

E4. Have you been diagnosed by a medical professional with any of the following mental health conditions? **(Cross <u>all</u> that apply)**

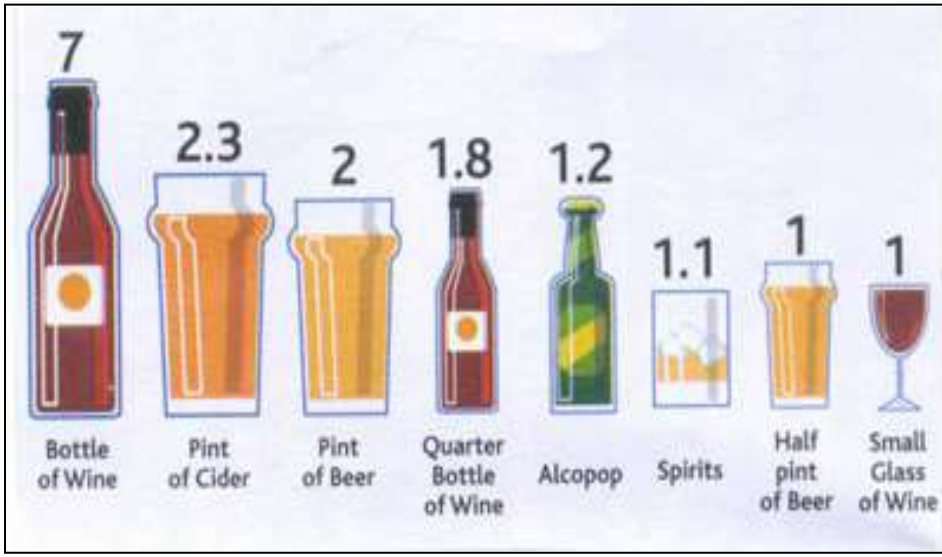
- ☐ 0) None
- ☐ i) Behavioural problem (please specify)
- ☐ ii) Anxiety
- ☐ iii) Phobia
- ☐ iv) Depression
- ☐ v)Manic depressive illness (Bipolar)
- ☐ vi) Schizophrenia
- ☐ vii) Other (please specify below)

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 ☐ Three to four hours per day

☐ One to two 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 <u>all</u> 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

We want to understand the impact that having a child with a cleft has on parents' wellbeing. To look at this, we need to understand what other stresses might be having an impact and also what support is available to people.

G1. 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	☐	☐	☐	☐	☐

G1 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	☐	☐	☐	☐	☐

G2. Below is a list of things that might be a problem for your **family**.

In the past **<u>one month, as a result of your child's health</u>**, 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	☐	☐	☐	☐	☐

G3. 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?	☐	☐	☐	☐	☐	☐

G3 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?	☐	☐	☐	☐	☐	☐

G3 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.

G4. 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?	☐	☐	☐	☐	☐

G5. 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

G5 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

G6. We are asking these questions to help us understand how children with cleft lip and/or palate develop.

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

	Not true	Somewhat true	Certainly true
a) Considerate of other people's feelings	☐	☐	☐
b) Restless, overactive, cannot stay still for long	☐	☐	☐
c) Often complains of headaches, stomach-aches or sickness	☐	☐	☐
d) Shares readily with other children (treats, toys, pencils etc)	☐	☐	☐
e) Often has temper tantrums or hot tempers	☐	☐	☐
f) Rather solitary, tends to play alone	☐	☐	☐
g) Generally obedient, usually does what adults request	☐	☐	☐
h) Many worries, often seems worried	☐	☐	☐
i) Helpful if someone is hurt, upset or feeling ill	☐	☐	☐
j) Constantly fidgeting or squirming	☐	☐	☐
k) Has at least one good friend	☐	☐	☐

G6 continued...

	Not true	Somewhat true	Certainly true
l) Often fights with other children or bullies them	☐	☐	☐
m) Often unhappy, down-hearted or tearful	☐	☐	☐
n) Generally liked by other children	☐	☐	☐
o) Easily distracted, concentration wanders	☐	☐	☐
p) Nervous or clingy in new situations, easily loses confidence	☐	☐	☐
q) Kind to younger children	☐	☐	☐
r) Often lies or cheats	☐	☐	☐
s) Picked on or bullied by other children	☐	☐	☐
t) Often volunteers to help others (parents, teachers, other children)	☐	☐	☐
u) Thinks things out before acting	☐	☐	☐
v) Steals from home, school or elsewhere	☐	☐	☐
w) Gets on better with adults than with other children	☐	☐	☐
x) Many fears, easily scared	☐	☐	☐
y) Sees tasks through to the end, good attention span	☐	☐	☐

G7. Overall, do you think that your child has difficulties in **one or more** of the following areas: emotions, concentration, behaviour or being able to get on with other people?

☐ Yes - minor difficulties ☐ Yes - severe difficulties

☐ Yes - definite difficulties ☐ No **If yes, go to question G8**
If no, go to question G9

G8. Please answer the following questions about these difficulties:

a) How long have these difficulties been present?

☐ Less than a month ☐ 1-5 months ☐ 6-12 months ☐ Over a year

b) Do the difficulties upset or distress your child?

☐ Not at all ☐ Only a little ☐ Quite a lot ☐ A great deal

c) Do the difficulties interfere with your child's everyday life in the following areas?

	Not at all	Only a little	Quite a lot	A great deal
i) Home life	☐	☐	☐	☐
ii) Friendships	☐	☐	☐	☐
iii) Classroom learning	☐	☐	☐	☐
iv) Leisure activities	☐	☐	☐	☐

d) Do the difficulties put a burden on you or the family as a whole?

☐ Not at all ☐ Only a little ☐ Quite a lot ☐ A great deal

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 regularly, sometimes, or not yet.

G9.	Yes	Some-times	Not yet
a) Without you giving help by pointing or repeating directions, does your child follow three directions that are unrelated to one another? For example, "Clap your hands, walk to the door, and sit down."	☐	☐	☐
b) Does your child use four and five word sentences? For example, does your child say, "I want the car"?	☐	☐	☐
c) When talking about something that has already happened, does your child use words that end in "-ed", such as "walked", "jumped", or "played"?	☐	☐	☐
d) Does your child use comparison words, such as "heavier," "stronger," or "shorter"?	☐	☐	☐
e) When you ask your child a question does he/she respond appropriately? For example, "What do you do when you are tired?", your child may say "go to sleep", "go to bed" or "lie down".	☐	☐	☐
f) Is your child able to repeat the following sentences back to you, without any mistakes? "Jane hides her shoes for Maria to find" and "Alex read the blue book under his bed"	☐	☐	☐

G10.	Yes	Some-times	Not yet
a) While standing, can your child throw a ball overhand in the direction of a person standing at least 6 feet away?	☐	☐	☐
b) Can your child catch a large ball with both hands?	☐	☐	☐
c) Without holding onto anything, can your child stand on one foot for at least 5 seconds without losing his/her balance and putting his/her foot down?	☐	☐	☐
d) Can your child walk on his/her tiptoes for 15 feet?	☐	☐	☐
e) Can your child hop forward on one foot for a distance of 4-6 feet without putting down the other foot?	☐	☐	☐
f) Can your child skip using alternating feet?	☐	☐	☐

G11.	Yes	Some-times	Not yet
a) If tracing a straight line on a piece of paper, can your child trace over the line without going off the line more than once?	☐	☐	☐
b) When drawing a picture of a person, does your child draw a person with a head, body, arms AND legs?	☐	☐	☐
c) When using scissors, can your child cut the paper in a more or less straight line?	☐	☐	☐
d) Is your child able to copy basic shapes (e.g. square, triangle, cross) accurately without tracing?	☐	☐	☐
e) Is your child able to copy letters (e.g. A, B, C) without tracing?	☐	☐	☐
f) Is your child able to copy their own name? (The letters can be overly large, backward or reversed)	☐	☐	☐

G12.	Yes	Some-times	Not yet
a) If shown three circles of varying size, is your child able to identify which circle is the smallest?	☐	☐	☐
b) Can your child identify five different colours (e.g. red, blue, yellow, black, white)?	☐	☐	☐
c) Can your child count up to 15 without making mistakes? (If your child can count to 12 without making mistakes, mark "sometimes")	☐	☐	☐
d) Can your child finish a sentence using a word that means the opposite of another word (e.g. "Ice is cold, and fire is ***hot***")?	☐	☐	☐
e) Does your child know the names of numbers if the number is written down (e.g. 1= one, 2 = two, 3 = three)?	☐	☐	☐
f) Can your child name at least four letters in his/her name if asked "what letter is this?"	☐	☐	☐

G13.	Yes	Some-times	Not yet
a) Can your child serve himself/herself, taking food from one container to another, using utensils?	☐	☐	☐
b) Can your child wash his/her hands and dry them with a towel without help?	☐	☐	☐
c) Can your child tell you at least four of the following? Their first name/age/city they live in/last name/gender/telephone number.	☐	☐	☐
d) Can your child dress and undress himself/ herself, including the use of buttons and zips?	☐	☐	☐
e) Can your child use the toilet by himself/herself?	☐	☐	☐
f) Does your child usually take turns and share with other children?	☐	☐	☐

G14. a) i. Do you think your child hears well? ii. **If no**, please explain.

☐ Yes ☐ No

b) i. Do you think your child talks like other children his/her age? ii. **If no**, please explain.

☐ Yes ☐ No

c) i. Can you understand most of what your child says? ii. **If no**, please explain.

☐ Yes ☐ No

d) i. Can other people understand most of what your child says? ii. **If no**, please explain.

☐ Yes ☐ No

e) i. Do you think your child walks, runs, and climbs like other children his/her age? ii. **If no**, please explain.

☐ Yes ☐ No

f) i. Does either parent have a family history of childhood deafness or hearing impairment? ii. **If yes**, please explain.

☐ Yes ☐ No

g) i. Do you have any concerns about your child's vision? ii. **If yes,** please explain.

☐ Yes ☐ No

h) i. Has your child had any medical problems in the last several months? ii. **If yes,** please explain.

☐ Yes ☐ No

i) i. Do you have any concerns about your child's behaviour? ii. **If yes**, please explain.

☐ Yes ☐ No

j) i. Does anything about your child worry you? ii. **If yes**, please explain.

☐ Yes ☐ No

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 your child cling to you more than you expect?	☐	☐	☐	☐
c) Does your child like to be hugged or cuddled?	☐	☐	☐	☐
d) Does your child talk and/or play with adults he/she knows well?	☐	☐	☐	☐
e) When upset can your child calm down within 15 minutes?	☐	☐	☐	☐
f) Does your child seem too friendly with strangers?	☐	☐	☐	☐
g) Can your child settle himself/herself down after periods of exciting activity?	☐	☐	☐	☐
h) Does your child seem happy?	☐	☐	☐	☐
i) Does your child cry, scream, or have tantrums for long periods of time?	☐	☐	☐	☐
j) Is your child interested in things around him/her such as people, toys and food?	☐	☐	☐	☐
k) Does your child go to the bathroom by himself/ herself? (Reminders and help with wiping are okay)	☐	☐	☐	☐
l) Does your child have eating problems (that are not related to their cleft) such as stuffing foods, vomiting or eating non-food items?	☐	☐	☐	☐

G15. continued...

	Most of the time	Some-times	Rarely or never	Cross if this is a concern
m) Can your child stay with activities he/she enjoys for at least 15 minutes (not including watching television)?	☐	☐	☐	☐
n) Do you and your child enjoy mealtimes together?	☐	☐	☐	☐
o) Does your child do what you ask him/her to do?	☐	☐	☐	☐
p) Does your child seem more active than other children his/her age?	☐	☐	☐	☐
q) Does your child sleep at least 8 hours in a 24 hour period?	☐	☐	☐	☐
r) Does your child use words to tell you what he/she wants or needs?	☐	☐	☐	☐
s) 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"?	☐	☐	☐	☐
t) Does your child move from one activity to the next with little difficulty, such as from playtime to mealtime?	☐	☐	☐	☐
u) Does your child explore new places, such as a park or a friend's home?	☐	☐	☐	☐
v) Does your child do things over and over and can't seem to stop? Examples include rocking or hand flapping.	☐	☐	☐	☐
w) Does your child hurt himself/herself on purpose?	☐	☐	☐	☐
x) Does your child follow rules (at home, at school)?	☐	☐	☐	☐

G15 continued...

	Most of the time	Some-times	Rarely or never	Cross if this is a concern
y) Does your child destroy or damage things on purpose?	☐	☐	☐	☐
z) Does your child stay away from dangerous things, such as fire and moving cars?	☐	☐	☐	☐
aa) Does your child show concern for other people's feelings? For example, does he/she look sad when someone is hurt?	☐	☐	☐	☐
bb) Do other children like to play with your child?	☐	☐	☐	☐
cc) Does your child like to play with other children?	☐	☐	☐	☐
dd) Does your child try to hurt other children, adults, or animals (for example, by kicking or biting)?	☐	☐	☐	☐
ee) Does your child take turns and share when playing with other children?	☐	☐	☐	☐
ff) Does your child show an interest or knowledge of adult sexual language and activity?	☐	☐	☐	☐
gg) Has anyone expressed concerns about your child's behaviours? If you cross "sometimes" or "most of the time" please specify in the box below.	☐	☐	☐	☐

G16. a) Are you happy with the outcome of your child's surgery so far?

☐ Very happy ☐ Neutral ☐ Very unhappy

☐ Quite happy ☐ Quite unhappy

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

☐ Not at all ☐ Quite noticeable

☐ A little ☐ Very noticeable

c) 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 has dominated 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 the impact of my child's cleft on their learning at school	☐	☐	☐	☐	☐
ix) I worry about the impact of my child's cleft on their self-confidence	☐	☐	☐	☐	☐
x) I worry about my child's future treatment	☐	☐	☐	☐	☐
xi) I feel comfortable talking to my child about their cleft	☐	☐	☐	☐	☐
xii) I feel optimistic about my child's future	☐	☐	☐	☐	☐
xiii) I feel that there are many positives to having a child with a cleft	☐	☐	☐	☐	☐

G16. d) If you feel that there are positives to having a child with cleft, please specify what these are in the box 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.

G17. Since your child's cleft was diagnosed, have you received any support from CLAPA?

☐ Yes ☐ No **If no, go to G22**

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

G18. 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)

G19. Do you still receive support from CLAPA?

☐ Yes, frequently ☐ Yes, occasionally ☐ No

G20. How often have you been satisfied with the support you have received from CLAPA?

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

G21. If applicable, when did you first hear about CLAPA?

☐ When my child was diagnosed ☐ When my child was born
☐ When my child was ☐ years old

G22. How many close friends do you have (other than your partner, if applicable)?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 or more

G23. Overall, how would you rate your relationships with your close friends?

☐ Poor ☐ Fair ☐ Good ☐ Excellent

G24. 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

G24 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

SECTION H - YOUR FAMILY

H1. a) Since the birth of your child with a cleft, have you had any more children?

☐ Yes ☐ No

If Yes b) How many? ☐

If Yes, please give us the following information
If No, please go to H2

i) Date of birth DD / MM / YY

ii) Gender
☐ Male
☐ Female

iii) What is their cleft type?
☐ This child does not have a cleft
☐ Cleft lip
☐ Cleft palate
☐ Cleft lip and palate
☐ Submucous cleft palate
☐ Not known

iv) Is their cleft:
☐ This child does not have a cleft
☐ Unilateral
☐ Bilateral
☐ Not known

v) Are they enrolled in the study?
☐ Yes
☐ No

---

c) Child 2

i) Date of birth DD / MM / YY

ii) Gender
☐ Male
☐ Female

iii) What is their cleft type?
☐ This child does not have a cleft
☐ Cleft lip
☐ Cleft palate
☐ Cleft lip and palate
☐ Submucous cleft palate
☐ Not known

iv) Is their cleft:
☐ This child does not have a cleft
☐ Unilateral
☐ Bilateral
☐ Not known

v) Are they enrolled in the study?
☐ Yes
☐ No

---

d) Child 3

i) Date of birth DD / MM / YY

ii) Gender
☐ Male
☐ Female

iii) What is their cleft type?
☐ This child does not have a cleft
☐ Cleft lip
☐ Cleft palate
☐ Cleft lip and palate
☐ Submucous cleft palate
☐ Not known

iv) Is their cleft:
☐ This child does not have a cleft
☐ Unilateral
☐ Bilateral
☐ Not known

v) Are they enrolled in the study?
☐ Yes
☐ No

H2. 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 H3**

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

---

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

---

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

H3. How long have you lived at your current address? ☐☐ Years ☐☐ Months

H4. In which way does your household occupy your current address? (**Cross <u>one</u> box only)**
- ☐ Buying it with the help of a mortgage or loan
- ☐ Owns it outright
- ☐ Rents it
- ☐ Lives here rent free (e.g. in a relative's or friend's property)
- ☐ Pays part rent and part mortgage (shared ownership)
- ☐ Don't know
- ☐ Other (please specify)

These questions ask you about **your partner**. Please fill in what you can.

H5. What is the highest educational qualification **your partner** has obtained? **(Cross one box only)**

- ☐ One or more O Levels/CSEs/GCEs (any grades)
- ☐ Five or more O Levels/CSEs (grade 1)/GCSEs (grades A*-C)/School Certificate
- ☐ One or more A Levels/AS Levels
- ☐ Two or more A Levels/Four or more AS Levels/Higher School Certificate
- ☐ NVQ Level 1/Foundation GNVQ
- ☐ NVQ Level 2/Intermediate GNVQ
- ☐ NVQ Level 3/Advanced GNVQ
- ☐ NVQ Levels 4-5/HNC/HND
- ☐ First degree (e.g. BA/BSc)
- ☐ Higher degree (e.g. MA, PhD, postgraduate PGCE)
- ☐ Other qualifications (e.g. City and Guilds, RSA/OCR, BTEC/Edexcel)
- ☐ Overseas qualifications (please specify)
- ☐ No qualifications
- ☐ Don't know
- ☐ Other (please specify)

H6. What is **your partner's** current employment status? **(Cross one box only)**

- ☐ Student
- ☐ At home
- ☐ Intern/apprentice
- ☐ Military Service
- ☐ Unemployed/laid off
- ☐ Rehabilitation/disabled
- ☐ Employed in public sector
- ☐ Employed in private sector
- ☐ Self-employed
- ☐ Other (please specify below)

H7. **This table shows income in weekly, monthly and annual amounts.** Which of the amounts on this list represents **YOUR PARTNER'S** individual total income from all jobs, tax credits, benefits and other sources **after tax** when added together? (**Cross <u>one</u> box only)**

Weekly Income after Tax	Monthly Income after Tax	Annual Income after Tax	
Less than £25	Less than £108	Less than £1,299	☐
£25 - £39	£109 - £175	£1,300 - £2,099	☐
£40 - £59	£176 - £259	£2,100 - £3,099	☐
£60 - £79	£260 - £350	£3,100 - £4,199	☐
£80 - £99	£351 - £433	£4,200 - £5,199	☐
£100 - £124	£434 - £542	£5,200 - £6,499	☐
£125 - £149	£543 - £650	£6,500 - £7,799	☐
£150 - £179	£651 - £775	£7,800 - £9,299	☐
£180 - £209	£776 - £917	£9,300 - £10,999	☐
£210 - £259	£918 - £1,125	£11,000 - £13,499	☐
£260 - £299	£1,126 - £1,333	£13,500 - £15,999	☐
£300 - £379	£1,334 - £1,667	£16,000 - £19,999	☐
£380 - £479	£1,668 - £2,083	£20,000 - £24,999	☐
£480 - £577	£2,084 - £2,500	£25,000 - £29,999	☐
£578 - £769	£2,501 - £3,333	£30,000 - £39,999	☐
£770 - £962	£3,334 - £4,167	£40,000 - £49,999	☐
£963 - £1,154	£4,168 - £5,000	£50,000 - £59,999	☐
£1,155 - £1,346	£5,001 - £5,833	£60,000 - £69,999	☐
£1,347 - £1,538	£5,834 - £6,667	£70,000 - £79,999	☐
£1,539 or more	£6,668 or more	£80,000 or more	☐

SECTION I - ADDITIONAL QUESTIONS FOR THE MOTHER

I1. 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

Office use only

www.bristol.ac.uk/cleft-collective.

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