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

ID LABEL

You and Your Child at 8 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

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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 and your child's eating and drinking behaviours
C. **Your Child's Teeth** - This section asks questions about your child's teeth and dentist
D. **Additional Questions About Your Child -** This section includes questions not covered in any other section, such as childcare and school
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

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 child' please answer in relation to your child who was born with a cleft. Some of the questions are retrospective. 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. How many weeks pregnant were you when you gave birth?

☐☐ **Weeks**

A2. What is your child's gender? ☐ Male ☐ Female

The answers to questions A3, A5 and A7 may be found in your child's red book (Personal Child Health Record) if available

A3. How much did your child weigh **at birth** (if known)?

Lbs ☐☐ Oz ☐☐ OR Kg ☐☐ . g ☐☐

A4. How much does your child weigh **now**?

Lbs ☐☐☐ Oz ☐☐ OR Kg ☐☐ . g ☐☐

A5. What was your child's height/length **at birth** (if known)?

Feet ☐ Inches ☐☐ OR Cm ☐☐ . Mm ☐

A6. What is your child's height **now**?

Feet ☐ Inches ☐☐ OR M ☐ . Cm ☐☐ . Mm ☐

A7. What was your child's head circumference **at birth** (if known)?

Inches ☐☐ OR Cm ☐☐ . Mm ☐

A8. What is your child's head circumference **now**?

Inches ☐☐ OR Cm ☐☐ . Mm ☐

A9. What type of cleft was your child born with?

☐ Cleft lip ☐ Cleft palate ☐ Cleft lip and palate

☐ Submucous cleft palate ☐ Don't know

A10. 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

A11. 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

A12. a) When was your child's cleft lip diagnosed (if applicable)?

☐ At the 20 week scan ☐ During a 3D scan ☐ At birth

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

☐☐ Weeks

A13. a) When was your child's cleft palate diagnosed (if applicable)?

☐ At the 20 week scan ☐ During a 3D scan ☐ At birth ☐ After birth (late diagnosis)

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

☐☐ Weeks

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

Years ☐☐ Weeks ☐☐ Days ☐☐

A14. a) Has your child had their lip repaired?

☐ Yes ☐ No ☐ Not applicable

If Yes b) How old was your child when they had their lip repaired?

Months ☐☐ Weeks ☐☐

A15. a) Has your child had their palate repaired?

☐ Yes ☐ No ☐ Not applicable

If Yes b) How old was your child when they had their palate repaired?

Months ☐☐ Weeks ☐☐

A16. Has your child had any other surgery relating to their cleft lip / cleft palate (e.g. grommets, bone graft, palate re-repair)?

a) ☐ Yes ☐ No **If Yes** b) please specify ☐

A17. 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) ☐

A18. 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 (please specify) ☐

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) ☐

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 (please specify)

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 (please specify)

f) Kidney and bladder problems

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

A19. Does your child have problems with the structural development of any of the following? **(Cross <u>all</u> that apply)**

- ☐ a) Eyes (not including vision impairments)
- ☐ b) Ears (not including hearing impairments)
- ☐ c) Cheekbones
- ☐ d) Jaw
- ☐ e) Tongue
- ☐ f) Hands
- ☐ g) Feet
- ☐ h) Spine
- ☐ i) Other development condition (please specify)
- ☐ j) None of the above

A20. Has **<u>your child</u>** been diagnosed with any of the following syndromes / genetic conditions? **(Cross <u>all</u> 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 (please specify)

☐ j) We are currently undergoing genetic testing at the hospital

☐ k) None

A21. Has **<u>your child</u>** ever had difficulties with any of the following? **(Cross <u>all</u> that apply)**

☐ a) Attention/concentration

☐ b) Hyperactivity

☐ c) Behavioural problems

☐ d) Emotional difficulties

☐ e) Social interaction

☐ f) Learning to read or write

☐ g) Movement

☐ h) Co-ordination

☐ i) Other (please specify)

☐ j) None

A22. a) Has **<u>your child</u>** been diagnosed with any of the following conditions?
(Cross <u>all</u> that apply)

- ☐ i) Attention Deficit/Hyperactivity Disorder (AD/HD)
- ☐ ii) Autism Spectrum Disorder
- ☐ iii) A learning disability
- ☐ iv) Dyslexia
- ☐ v) Depression
- ☐ vi) Anxiety
- ☐ vii) Dyspraxia
- ☐ viii) Speech-Sound Disorder
- ☐ ix) Chronic Fatigue Syndrome (CFS)/ME
- ☐ x) Other (Please specify) [ ]
- ☐ xi) None

A22. b) If you answered yes to question A22. a) x., please tell us more in the box below.

[ ]

A23. 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)

	i) You	ii) Child's father	iii) Other child	Date of birth
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) We are currently undergoing genetic testing at the hospital	☐	☐	☐	__ __ / __ __ / __ __
j) Other syndrome / genetic condition (please specify)	☐	☐	☐	__ __ / __ __ / __ __
k) No	☐	☐	☐	

SECTION B - FEEDING YOUR CHILD

B1. a) Were you able to feed your child directly from the breast?

☐ We tried but were unable to ☐ We didn't try ☐ Yes

If Yes b) How long did you breast feed your child? | | | | Weeks

If No c) How did you initially feed your child?

☐ MAM soft bottle (squeezy bottle)
☐ Haberman feeder bottle system
☐ With a normal feeding bottle or teat
☐ Other (please specify)

B2. Did you feed your child using.....

☐ Breast milk only (including feeding directly from the breast and expressed breast milk)

☐ Formula milk only

☐ A combination of breast milk and formula milk

B3. a) Did you have difficulties feeding your child in the first few months?

☐ Yes, great difficulty ☐ Yes, some difficulty
☐ No difficulties

If Yes b) Were you distressed by these difficulties?

☐ Yes, a great deal ☐ Yes, a little ☐ No

B4. Did your child initially require feeding assistance?

☐ Yes, with a feeding tube (Nasogastric Intubation, NGT)
☐ Yes, due to a blocked airway (Nasopharyngeal Airway, NPA)
☐ No

B5. Did your child have any nasal regurgitation (food coming down their nose)?

☐ Yes, often ☐ Yes, sometimes ☐ No

B6. Did your child have any difficulties swallowing?

☐ Yes, often ☐ Yes, sometimes ☐ No

B7. Approximately how old was your child when they first had something other than milk to drink (e.g. tap water, mineral water, fruit juice)?

☐☐ Months

B8. Approximately how old was your child when they were first given solids to eat (e.g. baby food in a jar, packet or tin, or homemade food such as baby rice, pureed fruit or vegetables)?

☐☐ Months

B9. Since your child was 6 months old, have they at any time:

	i) Yes and worried me greatly	ii) Yes and worried me a bit	iii) Sometimes	iv) Almost never
a) Not eaten a sufficient amount of food	☐	☐	☐	☐
b) Refused to eat the right food	☐	☐	☐	☐
c) Been choosy with food	☐	☐	☐	☐
d) Overeaten	☐	☐	☐	☐
e) Been difficult to get into an eating routine	☐	☐	☐	☐

f) Is this still a problem now? ☐Yes, always ☐Yes, sometimes ☐No

B10. a) Up to the age of **3 years**, did your child have difficulties with particular tastes or textures?

☐ Yes ☐ No

If Yes b) please specify

c) Is this still a problem now? ☐ Yes, always ☐ Yes, sometimes ☐ No

B11. When did your child first begin drinking from a cup or a beaker?

Months

B12. Up to the age of **3 years**, what did your child normally drink? **(Cross all that apply)**

☐ a) Water ☐ b) Milk ☐ c) Fruit juice

☐ d) Squash ☐ e) Fizzy drinks ☐ f) Other (please specify)

B13. What does your child normally drink now? **(Cross all that apply)**

☐ a) Water ☐ b) Milk ☐ c) Fruit juice

☐ d) Squash ☐ e) Fizzy drinks ☐ f) Other (please specify)

B14. Where does your child normally eat their meals? **(Cross all that apply)**

☐ a) At the table ☐ b) In front of the TV

☐ c) In their bedroom ☐ d) Other (please specify)

B15. Does your child normally eat... **(Cross all that apply)**

☐ a) Alone ☐ b) With siblings

☐ c) With the whole of the family ☐ d) Other (please specify)

B16. Does your child eat the same foods as the rest of the family?

☐ Usually ☐ Sometimes ☐ No

B17. Does your child have snacks in the day, between meals?

☐ No ☐ Once ☐ Twice ☐ More than twice

B18. Now that your child is 8 years old, 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 old was your child when they developed their first tooth?

☐☐ Months

C2. How many teeth does your child have now? ☐☐

C3. Did any of the adult back teeth or front teeth (incisors) come through with yellow/brown or opaque white patches?

☐ Yes ☐ No ☐ Don't know

C4. Before your child lost their top baby front teeth, were they ever accidentally damaged?

☐ Yes ☐ No

☐ Don't know ☐ My child still has their top baby front teeth

C5. Does your child have any extra baby teeth?

☐ Yes ☐ No ☐ Don't know

C6. Does your child have any extra adult teeth?

☐ Yes ☐ No ☐ Don't know

C7. Does your child have any missing permanent/adult teeth?

☐ Yes ☐ No ☐ Don't know

C8. When does your child brush their teeth?

☐ Morning ☐ Evening

☐ Morning and Evening ☐ Never

☐ Other (please specify) ☐

C9. What toothpaste is your child using?

☐ None ☐ Children's toothpaste (over 3 years) ☐ Adult toothpaste

C10. a) Does your child have a drink in the last hour before bed?

☐ Yes ☐ No

If Yes b) What does your child drink? **(Cross all that apply)**

☐ i) Water ☐ ii) Milk ☐ iii) Fruit juice

☐ iv) Squash ☐ v) Fizzy drinks ☐ vi) Other (please specify)

If Yes c) Does your child brush their teeth afterwards? ☐ Yes ☐ No

C11. a) Does your child drink in the night? ☐ Yes ☐ No

If Yes b) What does your child drink? **(Cross all that apply)**

☐ i) Water ☐ ii) Milk ☐ iii) Fruit juice

☐ iv) Squash ☐ v) Fizzy drinks ☐ vi) Other (please specify)

C12. Do you have a family dentist? ☐ Yes ☐ No

C13. How old was your child when you first took them to the dentist?

Years Months

☐ Don't know

☐ Not applicable

C14. Do you take your child to the dentist now?

☐ Yes, every four months ☐ Yes, every six months ☐ Yes, every year

☐ Yes, when in pain ☐ No

C15. Has your child ever been told they have dental caries (tooth decay)?

☐ Yes ☐ No ☐ Don't know

C16. Has your child had any of the following procedures? **(Cross all that apply)**

☐ a) Filling ☐ b) Metal Crown

☐ c) Tooth removed ☐ d) None of these

☐ e) Don't know

C17. a) Has your child ever been given something to make their mouth numb?

☐ Yes ☐ No ☐ Don't know

If Yes b) What did they have done to their teeth at this time?

☐ A filling ☐ A tooth pulled out ☐ I can't remember

☐ Other (please specify)

C18. a) Has your child ever been given something to make them go to sleep (general anaesthetic) before the dentist did something to their teeth?

☐ Yes ☐ No ☐ Don't know

If Yes b) What did they have done to their teeth at this time?

☐ A filling ☐ A tooth pulled out

☐ Don't know ☐ Other (please specify)

C19. Has the dentist ever talked to you about caring for your child's teeth?

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

C20. Has the dentist recommended that your child uses a daily fluoride mouthwash?

☐ Yes, after brushing ☐ Yes, at a separate time to brushing ☐ No

☐ Don't know ☐ Not applicable

C21. Does the dentist normally place fluoride varnish on your child's teeth?

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

C22. Has your child had fissure sealants (protective plastic coatings) put on their new adult molar teeth?

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

C23. Do you feel your family dentist is well informed about cleft lip/palate?

☐ My dentist is well informed

☐ My dentist knows a little

☐ Not at all

☐ Not applicable

C24. Are you happy with the care your child receives from your family dentist?

☐ Yes, always ☐ Yes, mostly ☐ Only sometimes

☐ Not at all ☐ Not applicable

C25. 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 ☐ ii) At the hospital

☐ iii) Somewhere else (please specify)

C26. a) Have you ever been given specialist advice about caring for your child's teeth because they were born with a cleft?

☐ Yes ☐ No ☐ Don't know

If Yes b) Who was it who provided this specialist information? **(Cross all that apply)**

☐ i) Someone from the cleft team

☐ ii) Hospital specialist

☐ iii) Family dentist

☐ iv) Hygienist or dental therapist

☐ v) Other (please specify)

SECTION D - ADDITIONAL QUESTIONS ABOUT YOUR CHILD

D1. In the first few months after your baby was born, what position was your baby...

a) When they went down for the night?

☐ i. Lying on their back ☐ ii. Lying on their side ☐ iii. Lying on their front

b) When they woke up?

☐ i. Lying on their back ☐ ii. Lying on their side ☐ iii. Lying on their front

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

D2. The following questions ask about who regularly looked after your child (apart from yourself and your partner) in their early years **(Cross <u>all</u> that apply)**

a) ☐ No one else looked after my child

Who looked after your child?	How old was your child when this person / organisation regularly looked after them?			On average how often did this person / organisation look after your child each week?			
	i) Between 6 & 12 months	ii) Between 12 & 18 months	iii) Between 18 months & 3 years	i) Less than 1 day per week	ii) 1 to 2 days per week	iii) 3 to 4 days per week	iv) More than 4 days per week
b) c) Child's grandparent	☐	☐	☐	☐	☐	☐	☐
d) e) Other relative	☐	☐	☐	☐	☐	☐	☐
f) g) Friend or neighbour	☐	☐	☐	☐	☐	☐	☐
h) i) Paid person outside the home (e.g.child -minder)	☐	☐	☐	☐	☐	☐	☐
j) k) Paid person inside the home (e.g. nanny /babysitter)	☐	☐	☐	☐	☐	☐	☐
l) m) Private day nursery or creche	☐	☐	☐	☐	☐	☐	☐
n) o) Local authority day nursery	☐	☐	☐	☐	☐	☐	☐
p) q)Pre-School or equivalent	☐	☐	☐	☐	☐	☐	☐
r) s) Other (please specify below)	☐	☐	☐	☐	☐	☐	☐

D3. 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 has regularly looked after your child since they started school **(Cross all that apply)**

D4. Apart from yourself and your partner, who has regularly looked 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)	☐	☐	☐	☐

D5. What type of school does your child attend?

☐ Primary school ☐ Special school

☐ Private or independent primary school ☐ Other (please specify)

D6. a) Does your child have any additional needs which mean the school should make (or has made) special arrangements (e.g. sit them at the front of the classroom/take them out of lessons/provide extra teaching or help)?

☐ Yes ☐ No

If Yes b) Please tell us which additional needs your child has which means special arrangements need to be made **(Cross <u>all</u> that apply)**

☐ i) A learning disability
☐ ii) Speech, language or communication
☐ iii) Hearing difficulties
☐ iv) Eyesight
☐ v) Physical problem
☐ vi) Reading difficulties
☐ vii) Emotional or behavioural problem
☐ viii) Other (please specify)

D7. Has your child been given a Statement of Special Educational Needs (SEN) or an Education, Health and Care Plan?

☐ Yes, my child has a statement/plan
☐ No, but my child is being assessed
☐ No, my child was refused a statement/plan
☐ No, my child has never been considered for a statement/plan

D8. If applicable, how happy are you with the special arrangements that have been made for your child?

☐ Very happy
☐ Somewhat happy
☐ Somewhat unhappy
☐ Very unhappy
☐ Not applicable

D9. Do you feel that you have a good relationship with your child's school?

☐ Yes, always
☐ Yes, most of the time
☐ Sometimes
☐ Not very often
☐ No

D10. a) Has your child ever received speech and language therapy? **(Cross <u>all</u> that apply)**

☐ i) Yes, from the cleft team
☐ ii) Yes, at school
☐ iii) Yes, other (please specify)
☐ iv) No

If Yes b) Is your child still receiving speech and language therapy? **(Cross <u>all</u> that apply)**

- ☐ i) Yes, from the cleft team
- ☐ ii) Yes, at school
- ☐ iii) Yes, other (please specify)
- ☐ iv) No

D11. In general, how happy are you with the progress your child is making at school?

☐ Very happy ☐ Somewhat happy ☐ Somewhat unhappy
☐ Very unhappy ☐ Not applicable

D12. How do you think your child feels about school?

My child...	**Always**	**Usually**	**Some -times**	**Not at all**
a) Looks forward to going	☐	☐	☐	☐
b) Enjoys it	☐	☐	☐	☐
c) Is stimulated by it	☐	☐	☐	☐
d) Is frightened by it	☐	☐	☐	☐
e) Talks about his/her friends	☐	☐	☐	☐
f) Seems bored by it	☐	☐	☐	☐
g) Likes the teacher(s)	☐	☐	☐	☐
h) Does not like school	☐	☐	☐	☐

D13. Do you have any other concerns about the time your child spends at school?

- ☐ No
- ☐ Yes (please tell us more)

SECTION E - YOUR FAMILY

E1. 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 E2

c) Child 1

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 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

---

e) 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

E2. 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? ☐☐

E3. How long have you lived in this current household arrangement?

☐☐ Years AND/OR ☐☐ Months AND/OR ☐☐ Weeks

E4. What is your current marital status?

☐ Single ☐ Domestic partner ☐ Married

☐ Separated ☐ Divorced ☐ Widowed

☐ Civil Union

E5. How long have you lived in this current marital arrangement?

☐☐ Years AND/OR ☐☐ Months AND/OR ☐☐ Weeks

E6. These questions ask about your relationship with your current partner (if applicable).

	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	☐	☐	☐	☐	☐

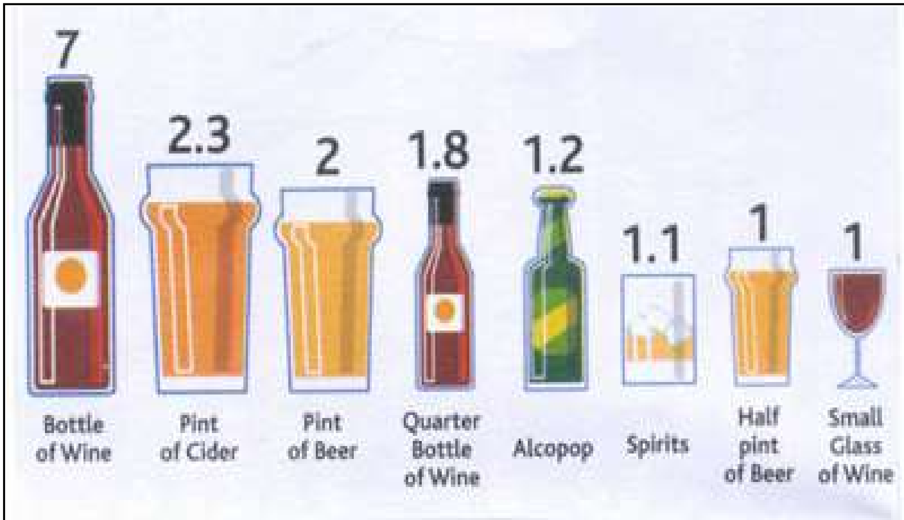
k) ☐ Not applicable **(please go to question F1)**

SECTION F - YOUR LIFESTYLE

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

If No please go to question F5.

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. On average, how often do you drink alcohol?

- ☐ Less than once per month
- ☐ One to three times per month
- ☐ One to two times per week
- ☐ Three to four times per week
- ☐ Every day or most days

F4. What type(s) of alcohol do you usually drink? **(Cross all that apply)**

- ☐ a) Beer
- ☐ b) Wine
- ☐ c) Spirits (such as vodka, gin, whisky)
- ☐ d) Fortified wines (such as sherry, port, Madeira)
- ☐ e) Mixed drink
- ☐ f) Other (please specify) ____________

F5. Do you currently smoke?

☐ Yes

☐ No **(Please go to question F8)**

F6. On average, how many cigarettes do you currently smoke **per day?**

☐ Less than one per day ☐ One per day

☐ Two to four per day ☐ ½ a pack (five to 14 per day)

☐ One pack (15-24 per day) ☐ One ½ packs (25-34 per day)

☐ Two packs (35-44 per day) ☐ More than two packs per day

F7. Where do you usually smoke?

☐ Only outside ☐ Only inside ☐ Both inside and outside

F8. a) Are you ever exposed to passive smoke (breathing in other people's smoke e.g. at home, work or during leisure time)? ☐ Yes ☐ No **(Please go to question F10)**

If Yes b) How many hours a day are you 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

F9. a) Is your child (born with a cleft) ever exposed to passive smoke? ☐ Yes ☐ No

If Yes b) How many hours a 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

F10. Do you currently use any other types of nicotine? **(Cross all that apply)**

☐ a) Nicotine gum ☐ b) Adhesive patch

☐ c) Nicotine sprays ☐ d) Nicotine inhalers

☐ e) Lozenges or tablets ☐ f) 'Snus' or nasal snuff

☐ g) Chewing tobacco ☐ h) Electronic cigarette

☐ i) None ☐ j) Other (please specify)

F11. 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)	☐	☐	☐	☐	☐	☐	☐

F12. 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

F13. On average, how much time do you spend outdoors with your child?

- ☐ Less than one hour per day
- ☐ One to two hours per day
- ☐ Three to four hours per day
- ☐ Five or more hours per day

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

G3. In the last year, did you experience 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 the following...

	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... (For example, 'Never happy', 'Often happy' etc)	Never	Some-times	Often	Almost always	Always	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	Some-times	Often	Almost always	Always	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	Some-times	Often	Almost always	Always	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

G9. 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	☐	☐	☐

G9 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	☐	☐	☐

G10. 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

G11. **If you have answered "Yes"**, 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

G12. a) Is your child currently having any treatment with your cleft team?

☐Yes ☐No ☐Don't know

If Yes, b) Please provide details below

G13. a) How noticeable do you think your child's cleft is to other people?

☐ Not at all noticeable ☐ A little noticeable

☐ Quite noticeable ☐ 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 worry that the cleft is affecting my relationship with my child	☐	☐	☐	☐	☐
iii) I worry about the impact of the cleft on my child's learning at school	☐	☐	☐	☐	☐
iv) I worry about the impact of the cleft on my child's self-confidence	☐	☐	☐	☐	☐
v) I worry about the impact of the cleft on my child's ability to get on with other children	☐	☐	☐	☐	☐
vi) I worry about any other treatment that my child might need	☐	☐	☐	☐	☐
vii) I feel comfortable talking to my child about their cleft	☐	☐	☐	☐	☐
viii) My child is able to explain to other people about their cleft	☐	☐	☐	☐	☐
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)	☐	☐	☐	☐	☐

G14. a) Do other people ever stare at your child because of their cleft?

☐ Yes ☐ No **If No, please go to question G15**

b) How often does this happen?

☐ Sometimes ☐ Once a week ☐ Every few days ☐ Every day

c) What does your child normally do in response to staring? **(Cross <u>all</u> that apply)**

☐ i) Gets upset ☐ ii) Gets angry

☐ iii) Ignores it ☐ iv) Tells someone

☐ v) Gives an explanation ☐ vi) Other (please specify)

d) How much do you think staring bothers your child?

☐ Not at all ☐ A little ☐ A lot

G15. a) Do other people ever ask your child questions or make comments about their appearance/speech?

☐ Yes ☐ No **If No, please go to question G16**

b) How often does this happen?

☐ Sometimes ☐ Once a week ☐ Every few days ☐ Every day

c) What does your child normally do in response to questions/comments? **(Cross <u>all</u> that apply)**

☐ i) Gets upset ☐ ii) Gets angry

☐ iii) Ignores it ☐ iv) Tells someone

☐ v) Answers the question or gives an explanation ☐ vi) Other (please specify)

d) How much do you think questions/comments bother your child?

☐ Not at all ☐ A little ☐ A lot

G16. a) Has your child ever been teased/bullied about their cleft?

☐ Yes ☐ No **If No, please go to question G17**

b) How often does this happen **<u>now</u>**?

☐ Never ☐ Sometimes ☐ Once a week

☐ Every few days ☐ Every day

c) What does your child normally do in response to teasing/bullying? **(Cross all that apply)**

☐ i) Gets upset ☐ ii) Gets angry

☐ iii) Ignores it ☐ iv) Tells someone

☐ v) Uses anti-bullying strategies such as humour, distraction or assertiveness ☐ vi) Other (please specify)

d) How much do you think teasing/bullying bothers your child?

☐ Not at all ☐ A little ☐ A lot

G17. Does your child ever avoid things because of their appearance/speech (for example, joining in activities or having their photograph taken)?

☐ No

☐ Yes (please specify)

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.

G18. Since your child's cleft was diagnosed, have you received any support from CLAPA? ☐ Yes ☐ No **If no, go to section H**

G19. 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)

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

☐ Never ☐ Sometimes ☐ Often

☐ Almost always ☐ Always

G21. When did you first hear about CLAPA (if applicable)?

☐ When my child was diagnosed ☐ When my child was born

☐ When my child was ☐ years old

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 never lived at home / left the home before child was born ☐

H2. a) Does the child's biological father have a cleft lip or cleft palate? ☐ Yes ☐ No

If Yes b) What type of cleft?

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

c) Is their cleft:

- ☐ Unilateral
- ☐ Bilateral
- ☐ Not known

H3. a) To the best of your knowledge, have any of the biological father's relatives been diagnosed with a cleft lip or cleft palate? ☐ Yes ☐ No

If Yes

b) i) Please tell us who?

☐

ii) What is their cleft type?

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

iii) Is their cleft:

- ☐ Unilateral
- ☐ Bilateral
- ☐ Not known

c) i) Please tell us who?

☐

ii) What is their cleft type?

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

iii) Is their cleft:

- ☐ Unilateral
- ☐ Bilateral
- ☐ Not known

d) i) Please tell us who?

☐

ii) What is their cleft type?

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

iii) Is their cleft:

- ☐ Unilateral
- ☐ Bilateral
- ☐ Not known

SECTION Z

Z1. This questionnaire was completed by:

a) Child's biological mother ☐

b) Someone else (please specify) ☐

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:

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Oakfield Grove
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