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

ID LABEL

You and Your Child at 12 years

Mother's questionnaire

This questionnaire is for the child's mother.

University of BRISTOL
The Underwood Trust
THE SCAR FREE FOUNDATION
VTCT WORLD CLASS QUALIFICATIONS

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For office use only

About this research

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

About this questionnaire

This questionnaire has six sections:

A. **Your Child's Health** - This section asks you questions related to the health of your child
B. **Your Child's Speech & Language Skills** - This section asks about your child's speech and language development
C. **Your Child's Teeth** - This section asks questions about your child's teeth and dental treatment
D. **Additional Questions About Your Child -** This section includes questions not covered in any other section
E. **Your Family** - This section asks questions about your other children (if applicable)
F. **Your Child's Wellbeing** - This sections asks about how your child has been feeling recently
G. **Your Wellbeing** - This section asks about how you have been feeling recently
H. **Additional Questions For The Mother** - This section includes questions not covered in any other section

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, and the impact of having a 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 or GP who can help.

Thank you for completing this questionnaire!

SECTION A - YOUR CHILD'S HEALTH

A1. What is your child's biological sex?

☐ Male ☐ Female

A2. How much does your child weigh **now**?

Stones ☐☐ Lbs ☐☐ OR Kg ☐☐ . ☐☐

A3. What is your child's height **now**?

Feet ☐ Inches ☐☐ OR M ☐ . Cm ☐☐

A4. What is your child's head circumference **now**?

Inches ☐☐ OR Cm ☐☐ . Mm ☐

A5. What type of cleft was your child born with?

☐ Cleft lip ☐ Cleft palate ☐ Cleft lip and palate

☐ Submucous cleft palate ☐ Don't know

A6. Is your child's cleft unilateral (on one side of their mouth) or bilateral (on both sides of their mouth)?

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

A7. 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

A8. After your child's primary cleft repair have they had any other surgery relating to their cleft lip / cleft palate? **(Cross <u>all</u> that apply)**

☐ a) Grommets ☐ b) Bone graft ☐ c) Speech surgery

☐ d) Palate re-repair ☐ e) Lip revision ☐ f) Fistula repair

☐ g) Other (please specify below) ☐ h) None of the above

A9. How many cleft related surgeries has your child had since birth?

☐☐

A10. How old was your child when they received the following surgeries?

	My child has not had this surgery	Age in months	OR	Age in years
a) Lip adhesion	☐	☐☐		☐☐
b) Primary lip repair	☐	☐☐		☐☐
c) Primary palate repair	☐	☐☐		☐☐
d) Palate re-repair	☐	☐☐		☐☐
e) Fistula repair	☐	☐☐		☐☐
f) Buccinator flaps	☐	☐☐		☐☐
g) Pharyngoplasty	☐	☐☐		☐☐

A11. Has your child had any of the following infections? **(Cross <u>all</u> that apply)**

☐ a) None
☐ b) German measles (Rubella)
☐ c) Measles
☐ d) Chickenpox
☐ e) Mumps
☐ f) Meningitis
☐ g) Urinary tract infection (E.g. cystitis)
☐ h) Chest infections / pneumonia
☐ i) Recurrent ear infections
☐ j) COVID-19

A12. Has your child had / does your child have any of the following conditions or problems?

a) Neurological / Sensory Conditions (Cross all that apply)

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

b) Heart / Lungs / Immune system (Cross all that apply)

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

c) Skin / Musculoskeletal conditions (Cross all that apply)

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

d) Metabolic conditions (Cross all that apply)

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

e) Abdominal conditions (Cross all that apply)

- ☐ 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 below)

f) Kidney and bladder problems (Cross all that apply)

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

A13. Does your child have problems with the structural development of any of the following? **(Cross all 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 developmental condition (please specify below)
- ☐ j) None of the above

A14. Has **your child** been diagnosed with any of the following syndromes / genetic conditions? **(Cross all that apply)**

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

A15. Has **your child** ever had difficulties with any of the following? **(Cross all 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 below)
- ☐ j) None

A16a. Has **your child** been diagnosed with any of the following conditions? If yes, please tells us how old your child was when they were diagnosed.

	No	Yes	Age at diagnosis in years
i) Attention Deficit Hyperactivity Disorder (ADHD)	☐	☐	
ii) Autism Spectrum Disorder	☐	☐	
iii) A learning disability	☐	☐	
iv) Dyslexia	☐	☐	
v) Depression	☐	☐	
vi) Anxiety	☐	☐	
vii) Dyspraxia	☐	☐	
viii) Speech-Sound Disorder	☐	☐	
ix) Developmental Language Disorder	☐	☐	
x) Chronic Fatigue Syndrome (CFS/ME)	☐	☐	
xi) Other (please specify below)	☐	☐	

A16b. If you answered yes to any of question A16a, please tell us more in the box below

A16c. Has your child been diagnosed with any other condition not mentioned above?

A17. Have **you, the child's biological father, or any of your other children** been diagnosed with any of the following syndromes / genetic conditions? (For other children, please also give their date of birth)

	You	Child's father	Other child	Other child's DOB DD / MM / YY
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 below)	☐	☐	☐	/ /
k) No	☐	☐	☐	

A18. Does your child have a regular sleeping routine?
☐Yes ☐No

A19. How often during the night does your child usually wake?
☐ times

A20. In the past year has your child regularly:	Yes, but did not worry me	Yes, and worried me a bit	Yes, and worried me greatly	No, did not happen	Don't know
a) Refused to go to bed	☐	☐	☐	☐	☐
b) Woken very early	☐	☐	☐	☐	☐
c) Had difficulty going to sleep	☐	☐	☐	☐	☐
d) Had nightmares	☐	☐	☐	☐	☐
e) Continued to get up after being put to bed	☐	☐	☐	☐	☐
f) Got up after only a few hours sleep	☐	☐	☐	☐	☐

A21a. While sleeping, does your child:	Yes	No	Don't know
i) Snore more than half the time?	☐	☐	☐
ii) Always snore?	☐	☐	☐
iii) Snore loudly?	☐	☐	☐
iv) Have "heavy" or loud breathing?	☐	☐	☐
v) Have trouble breathing, or struggle to breathe?	☐	☐	☐

A21b. Have you ever seen your child stop breathing during the night?

☐ Yes ☐ No ☐ Don't know

A21c. Does your child:	Yes	No	Don't know
i) Tend to breathe through the mouth during the day?	☐	☐	☐
ii) Have a dry mouth on waking up in the morning?	☐	☐	☐
iii) Occasionally wet the bed?	☐	☐	☐

A21d. Does your child:	Yes	No	Don't know
i) Wake up feeling unrefreshed in the morning?	☐	☐	☐
ii) Have a problem with sleepiness during the day?	☐	☐	☐

A21e. Has a teacher or other supervisor commented that your own child appears sleepy during the day?

☐ Yes ☐ No ☐ Don't know

A21f. Is it hard to wake your child up in the morning?

☐ Yes ☐ No ☐ Don't know

A21g. Does your child wake up with headaches in the morning?

☐ Yes ☐ No ☐ Don't know

A21h. Did your child stop growing at a normal rate at any time since birth?

☐ Yes ☐ No ☐ Don't know

A21i. Is your child overweight?

☐ Yes ☐ No ☐ Don't know

A21j. Your child often:	Yes	No	Don't know
i) Does not seem to listen when spoken to directly	☐	☐	☐
ii) Has difficulty organising tasks and activities	☐	☐	☐
iii) Is easily distracted by extraneous stimuli	☐	☐	☐
iv) Fidgets with hands or feet, or squirms in seat	☐	☐	☐
v) Is "on the go" or often acts as if "driven by a motor"	☐	☐	☐
vi) Interrupts or intrudes on others (eg. butts into conversations or games)	☐	☐	☐

A22a. Has your child previously had any nasal regurgitation (food coming down their nose)?

☐ Yes, often ☐ Yes, sometimes ☐ No

If yes, b). Does your child have any nasal regurgitation now?

☐ Yes, often ☐ Yes, sometimes ☐ No

We are asking the following questions to help inform cleft research into how children develop as they approach adolescence

A23. Has your child started to have hair growing in their armpits?

☐ Yes ☐ No ☐ Don't know

A24. Has your child started to have hair growing in their pubic area?

☐ Yes ☐ No ☐ Don't know

A25a. If your child is female, has she started her menstrual periods yet?

☐ Child is male ☐ Yes ☐ No ☐ Don't know

If yes, b). How old was your child when she had her first period?

☐☐ Age in years

A26. If your child is male, has his voice changed at all?

☐ No, it is the same ☐ Yes, occasionally it is a lot lower ☐ Yes, it has changed totally

☐ Not sure ☐ Child is female

SECTION B - YOUR CHILD'S SPEECH & LANGUAGE SKILLS ■

B1a. I am concerned about my child's talking…
☐ Never ☐ Rarely ☐ Often ☐ Always

B1b. Compared to other children, my child's speech is…
☐ Not different ☐ Slightly different ☐ Quite different ☐ Very different

B1c. My child avoids talking on the phone because of how they sound…
☐ Never ☐ Rarely ☐ Often ☐ Always

B1d. My child finds it easy talking with family...
☐ All the time ☐ Most of the time ☐ Some of the time ☐ Never

B1e. My child's friendships are affected because of how they sound...
☐ Never ☐ Rarely ☐ Often ☐ Always

B1f. My child avoids talking/answering questions in class...
☐ Never ☐ Rarely ☐ Often ☐ Always

B1g. My child finds it difficult to talk to new people...
☐ Never ☐ Rarely ☐ Often ☐ Always

B1h. I think my child finds talking tiring/effortful...
☐ Never ☐ Rarely ☐ Often ☐ Always

B1i. My child gets upset because of their speech
☐ Never ☐ Some of the time ☐ Most of the time ☐ All of the time

B1j. People make negative comments about my child's speech
☐ Never ☐ Some of the time ☐ Most of the time ☐ All of the time

i). How does this make you feel?

■

B1k. How has your child's speech impacted on their life?

B1l. Is there anything you would like to change about your child's speech?

☐ Yes ☐ No

If yes, i). What would you like to change?

B1m. Are there any situations your child finds difficult because of their talking? Which ones?

B2a. Has your child ever received intervention from 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 below)
- ☐ iv) No ***IF NO, GO TO SECTION C***

If yes, b). Has your child ever received speech and language therapy intervention for the difficulties they have making speech?

- ☐ Yes ☐ No ***IF NO, GO TO SECTION C***
- ☐ Don't know

If yes, c). 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 below) ☐ iv) No ***IF NO, GO TO SECTION C***

If yes, d). What speech, language or communication needs does your child have?
(Cross <u>all</u> that apply)

- ☐ i) Difficulty with making speech
- ☐ ii) Difficulty understanding aspects of language
- ☐ iii) Difficulties with using language effectively (e.g., struggles to know which words to use or difficulties making sentences)
- ☐ iv) Stammering
- ☐ v) Social communication
- ☐ vi) Other (please specify below)
- ☐ vii) Don't know
- ☐ viii) None of the above

SECTION C - YOUR CHILD'S TEETH

C1. How many teeth does your child have now?

C2. 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

C3. Does your child have any extra adult teeth?

☐ Yes ☐ No ☐ Don't know

C4. Does your child have any missing permanent/adult teeth? (Not because they were removed by a dentist)

☐ Yes ☐ No ☐ Don't know

C5. When does your child brush their teeth? (cross one box)

☐ Morning ☐ Evening ☐ Morning and Evening

☐ Never ☐ Other (please specify below)

C6. Do you help your child with brushing?

☐ Never ☐ Sometimes ☐ Always

C7. What toothpaste is your child using?

☐ None ☐ Children's toothpaste (over 6 years)

☐ Adult toothpaste ☐ High fluoride toothpaste

☐ Other (please specify below)

C8. 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

C9a. Does your child have a drink in the last hour before bed?

☐ Yes, always ☐ Yes, sometimes ☐ 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 below)

If Yes, c). Does your child brush their teeth afterwards?

☐ Yes ☐ No

C10. Does your child eat in the last hour before bed?

☐ Yes ☐ Yes, sometimes ☐ No

C11a. How often do you **as a family** see a dentist (approximately)

☐ Never ☐ Every 3 months ☐ Every 6 months

☐ Every 9 months ☐ Every 12 months ☐ Less often than once a year

C11b. How often does **your child** see a dentist (approximately)

☐ Never ☐ Every 3 months ☐ Every 6 months

☐ Every 9 months ☐ Every 12 months ☐ Less often than once a year

C12. How old was your child when you first took them to the dentist?

Years ☐☐ Months ☐☐

☐ Don't know

☐ Not applicable

C13. Has your child ever been told they have dental caries (tooth decay)?

☐ Yes ☐ No ☐ Don't know

C14. 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

C15. Has your child ever had gas and air inhalational sedation to help them have dental treatment?

☐ Yes ☐ No ☐ Don't know

C16a. Has your child ever had a general anaesthetic for dental treatment?

☐ Yes ☐ No ☐ Don't know

If yes, b). How long did it take to travel to the dental appointment where your child had a general anaesthetic?

☐ Less than 30 minutes ☐ 30 - 59 minutes

☐ 1 - 2 hours ☐ More than 2 hours

C17. If you have other children **without a cleft** have you received different advice about tooth brushing for your child born with a cleft?

☐ Yes ☐ No ☐ Not applicable

C18. Does the dentist normally place fluoride varnish on your child's teeth?

☐ Yes, every 3 months ☐ Yes, every 4 months ☐ Yes, every 6 months

☐ Yes, every year ☐ No ☐ Don't know

C19a. Do you like the way your child's teeth look now?

☐ Yes ☐ No

If no, b). What don't you like about them? **(Cross <u>all</u> that apply)**

☐ i) Teeth are gappy ☐ ii) Crooked ☐ iii) Too small

☐ iv) Too big ☐ v) Too brown ☐ vi) Too white

☐ vii) Blotchy ☐ viii) Other (please specify below)

C20a. Has your child had an orthodontic assessment by the Cleft Team Orthodontist?

☐ Yes ☐ No ***IF NO, GO TO QUESTION C21***

☐ Don't know

C20b. How old was your child at the first orthodontic assessment?

Years ☐☐ Months ☐☐ ☐ Don't know

C20c. If the assessment was carried out by a Cleft Team, who did it include?:

(Cross <u>all</u> that apply)

☐ i) Paediatric dentist ☐ ii) Orthodontist ☐ iii) Surgeon ☐ iv) Don't know

C20d. Were you advised that orthodontic treatment was necessary?

☐ Yes ☐ No ☐ Don't know

C20e. Were you advised that early treatment prior to the age of 12 would be needed to correct teeth that were far out of line?

☐ Yes ☐ No ☐ Don't know

C20f. Were you advised that your child would be monitored regularly by the cleft unit until they were ready for orthodontic treatment when more adult teeth were present?

☐ Yes ☐ No ☐ Don't know

C21a. Has your child attended a specific Bone Graft Clinic or an appointment about bone grafting?

☐ Yes ☐ No ***IF NO, GO TO QUESTION C22***

C21b. Were you advised that a bone graft was required?

☐ Yes ☐ No ***IF NO, GO TO QUESTION C22***

C21c. Did your child require orthodontic/brace treatment prior to the alveolar bone graft?

☐ Yes ☐ No

C21d. Approximately how long did the treatment take before the bone graft?

☐ 6 - 11 months ☐ 12 - 17 months ☐ 18 + months

☐ My child is still undergoing treatment ☐ Not applicable

C21e. How many days did your child stay in hospital to have the graft carried out?

☐☐ Days ☐ Not applicable ☐ My child is still undergoing treatment

C21f. Were there any complications with the graft?

☐ Yes ☐ No ☐ Not applicable

C22a. Is your child wearing, or has your child worn braces? **(Cross <u>all</u> that apply)**

☐ i) Yes, fixed braces (train tracks) ☐ ii) Yes, removable braces ☐ iii) None

C22b. If braces were fitted as part of your child's bone graft, how long after the operation were the braces removed?

☐ 6 - 11 months ☐ 12 - 17 months ☐ 18 + months ☐ Not applicable

☐ My child is still undergoing treatment

SECTION D - 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.

D1. What type of school does your child attend?

- ☐ Secondary school
- ☐ Special school
- ☐ Private or independent secondary school
- ☐ Other (please specify below)

D2a. Does your child have any additional needs which means 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 all that apply)**

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

D3. Has your child been given an Education, Health and Care (EHC) Plan, an Individual Development Plan (IDP) or a Statement of Special Educational Needs (SEN)?

- ☐ Yes, my child has an EHC plan, IDP or Statement
- ☐ No, but my child is being assessed
- ☐ No, my child was refused an EHC plan, IDP or Statement
- ☐ No, my child has never been considered for an EHC plan, IDP or Statement

D4. 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

D5. 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

D6. 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

D7. How do you think your child feels about school?

My child...	**Always**	**Usually**	**Sometimes**	**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	☐	☐	☐	☐

D8. Do you have any other concerns about the time your child spends at school?

☐ No ☐ Yes (please tell us more below)

D9. Which hand does your child write with?

☐ Left ☐ Right ☐ Both

☐ Don't know ☐ Not applicable to my child

D10. Which foot does your child use to kick a ball?

☐ Left ☐ Right ☐ Both

☐ Don't know ☐ Not applicable to my child

SECTION E - YOUR FAMILY

E1a. Since the birth of your child with a cleft, have you had any more children?

☐ Yes ☐ No ***IF NO, GO TO SECTION F***

If Yes, b). How many? ☐ If you have had more than 3 children, please give their details in the comments section at the end of the form (p41).

E1c. Child 1's details

i) Date of birth DD / MM / YY

ii) Biological sex
- ☐ 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

E1d. Child 2's details

i) Date of birth DD / MM / YY

ii) Biological sex
- ☐ 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

E1e. Child 3's details

i) Date of birth DD / MM / YY

ii) Biological sex
- ☐ 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

SECTION F - YOUR CHILD'S WELLBEING

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 or GP who can help.

F1. 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	☐	☐	☐
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	☐	☐	☐

F1. Continued...

	Not true	Somewhat true	Certainly true
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	☐	☐	☐

F2. 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 NO, GO TO QUESTION F4***

If you have answered "yes" to F2, please answer the following questions about these difficulties:

F3a. How long have these difficulties been present?

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

F3b. Do the difficulties upset or distress your child?

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

F3c. 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	☐	☐	☐	☐

F3d. 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

F4. These questions are about how **your child** may have been feeling or acting recently. For each question, please say how much he/she has felt or acted this way in the **past two weeks.**

In the past two weeks my child...	True	Sometimes true	Not true
a) Felt miserable or unhappy	☐	☐	☐
b) Didn't enjoy anything at all	☐	☐	☐
c) Felt so tired that he/she just sat around and did nothing	☐	☐	☐
d) Was very restless	☐	☐	☐
e) Felt like he/she was no good anymore	☐	☐	☐
f) Cried a lot	☐	☐	☐
g) Found it hard to think properly or concentrate	☐	☐	☐
h) Hated him/herself	☐	☐	☐
i) Felt he/she was a bad person	☐	☐	☐
j) Felt lonely	☐	☐	☐
k) Thought nobody really loved him/her	☐	☐	☐
l) Thought he/she could never be as good as other kids	☐	☐	☐
m) Felt he/she did everything wrong	☐	☐	☐

F5. Below is a list of sentences that describe how people feel. For each statement, please tick the response that seems to describe **your child** for **the last 3 months.** Please respond to all statements as well as you can, even if some do not seem to concern your child.

	Not true or hardly ever true	Somewhat true or sometimes true	Very true or often true
a) When my child feels frightened it is hard for them to breathe	☐	☐	☐
b) My child gets headaches when they are at school	☐	☐	☐
c) My child doesn't like to be with people they don't know well	☐	☐	☐
d) My child gets scared if they sleep away from home	☐	☐	☐
e) My child worries about other people liking them	☐	☐	☐
f) When my child gets frightened, they feel like passing out	☐	☐	☐
g) My child is nervous	☐	☐	☐

F5. Continued...

	Not true or hardly ever true	Somewhat true or sometimes true	Very true or often true
h) My child follows me wherever I go	☐	☐	☐
i) People tell me that my child looks nervous	☐	☐	☐
j) My child feels nervous with people they don't know well	☐	☐	☐
k) My child gets stomach-aches at school	☐	☐	☐
l) When my child gets frightened, they feel like they are going crazy	☐	☐	☐
m) My child worries about sleeping alone	☐	☐	☐
n) My child worries about being as good as other kids	☐	☐	☐
o) When my child gets frightened, they feel like things are not real	☐	☐	☐
p) My child has nightmares about something bad happening to their parents	☐	☐	☐
q) My child worries about going to school	☐	☐	☐
r) When my child gets frightened, their heart beats fast	☐	☐	☐
s) They get shaky	☐	☐	☐
t) My child has nightmares about something bad happening to them	☐	☐	☐
u) My child worries about things working out for them	☐	☐	☐
v) When my child gets frightened, they sweat a lot	☐	☐	☐
w) My child is a worrier	☐	☐	☐
x) My child gets really frightened for no reason at all	☐	☐	☐
y) My child is afraid to be alone in the house	☐	☐	☐
z) It is hard for my child to talk with people they don't know well	☐	☐	☐
aa) When my child gets frightened, they feel like they are choking	☐	☐	☐
bb) People tell me that my child worries too much	☐	☐	☐
cc) My child doesn't like to be away from their family	☐	☐	☐
dd) My child is afraid of having anxiety (or panic) attacks	☐	☐	☐

F5 continued...	Not true or hardly ever true	Somewhat true or sometimes true	Very true or often true
ee) My child worries that something bad might happen to their parents	☐	☐	☐
ff) My child feels shy with people they don't know well	☐	☐	☐
gg) My child worries about what is going to happen in the future	☐	☐	☐
hh) When my child gets frightened, they feel like throwing up	☐	☐	☐
ii) My child worries about how well they do things	☐	☐	☐
jj) My child is scared to go to school	☐	☐	☐
kk) My child worries about things that have already happened	☐	☐	☐
ll) When my child gets frightened, they feel dizzy	☐	☐	☐
mm) My child feels nervous when they are with other children or adults and they have to do something while they watch them (for example: read aloud,speak, play a game, play a sport)	☐	☐	☐
nn) My child feels nervous when they are going to parties, dances, or any place where there will be people they don't know well	☐	☐	☐
oo) My child is shy	☐	☐	☐

F6. For each statement that follows, please tick the response that best describes your child's behaviour **over the last 6 months**

	Not true	Sometimes true	Often true	Almost always true
a) Seems much more fidgety in social situations than when alone	☐	☐	☐	☐
b) Expressions on his or her face don't match what he or she is saying	☐	☐	☐	☐
c) Seems self-confident when interacting with others	☐	☐	☐	☐
d) When under stress, he or she shows rigid or inflexible patterns of behaviour that seem odd	☐	☐	☐	☐
e) Doesn't recognise when others are trying to take advantage of him or her	☐	☐	☐	☐

F6. Continued...

	Not true	Sometimes true	Often true	Almost always true
f) Would rather be alone than with others	☐	☐	☐	☐
g) Is aware of what others are thinking or feeling	☐	☐	☐	☐
h) Behaves in ways that seem strange or bizarre	☐	☐	☐	☐
i) Clings to adults, seems too dependant on them	☐	☐	☐	☐
j) Takes things too literally and doesn't get the real meaning of a conversation	☐	☐	☐	☐
k) Has good self-confidence	☐	☐	☐	☐
l) Is able to communicate his or her feelings to others	☐	☐	☐	☐
m) Is awkward in turn-taking interactions with peers (for example, doesn't seem to understand the give and take of conversations)	☐	☐	☐	☐
n) Is not well coordinated	☐	☐	☐	☐
o) Is able to understand the meaning of other people's tone of voice and facial expressions	☐	☐	☐	☐
p) Avoids eye contact or has unusual eye contact	☐	☐	☐	☐
q) Recognises when something is unfair	☐	☐	☐	☐
r) Has difficulty making friends, even when trying his or her best	☐	☐	☐	☐
s) Gets frustrated trying to get ideas across in conversations	☐	☐	☐	☐
t) Shows unusual sensory interests (for example, mouthing or spinning objects) or strange ways of playing with toys	☐	☐	☐	☐
u) Is able to imitate others' actions	☐	☐	☐	☐
v) Plays appropriately with children his or her age	☐	☐	☐	☐
w) Does not join group activities unless told to do so	☐	☐	☐	☐
x) Has more difficulty than other children with changes in his or her routine	☐	☐	☐	☐
y) Doesn't seem to mind being out of step with or 'not on the same wavelength' as others	☐	☐	☐	☐
z) Offers comfort to others when they are sad	☐	☐	☐	☐

F6. Continued...	Not true	Sometimes true	Often true	Almost always true
aa) Avoids starting social interactions with peers or adults	☐	☐	☐	☐
bb) Thinks or talks about the same thing over and over	☐	☐	☐	☐
cc) Is regarded by other children as odd or weird	☐	☐	☐	☐
dd) Becomes upset in a situation with lots of things going on	☐	☐	☐	☐
ee) Can't get his or her mind off something once he or she starts thinking about it	☐	☐	☐	☐
ff) Has good personal hygiene	☐	☐	☐	☐
gg) Is socially awkward, even when he or she is trying to be polite	☐	☐	☐	☐
hh) Avoids people who want to be emotionally close to him or her	☐	☐	☐	☐
ii) Has trouble keeping up with the flow of a normal conversation	☐	☐	☐	☐
jj) Has difficulty relating to adults	☐	☐	☐	☐
kk) Has difficulty relating to peers	☐	☐	☐	☐
ll) Responds appropriately to mood changes in others (for example, when a friend's or playmate's mood changes from happy to sad)	☐	☐	☐	☐
mm) Has an unusually narrow range of interests	☐	☐	☐	☐
nn) Is imaginative, good at pretending (without losing touch with reality)	☐	☐	☐	☐
oo) Wanders aimlessly from one activity to another	☐	☐	☐	☐
pp) Seems overly sensitive to sounds, textures or smells	☐	☐	☐	☐
qq) Separates easily from caregivers	☐	☐	☐	☐
rr) Doesn't understand how events relate to one another (cause and effect) the way other children his or her age do	☐	☐	☐	☐
ss) Focuses his or her attention to where others are looking or listening	☐	☐	☐	☐
tt) Has overly serious facial expressions	☐	☐	☐	☐
uu) Is too silly or laughs inappropriately	☐	☐	☐	☐

F6. Continued...	Not true	Sometimes true	Often true	Almost always true
vv) Has a sense of humour, understands jokes	☐	☐	☐	☐
ww) Does extremely well at a few tasks, but does not do as well at most other tasks	☐	☐	☐	☐
xx) Has repetitive, odd behaviours such as hand flapping or rocking	☐	☐	☐	☐
yy) Has difficulty answering questions directly and ends up talking around the subject	☐	☐	☐	☐
zz) Knows when he or she is talking too loud or making too much noise	☐	☐	☐	☐
aaa) Talks to people with an unusual tone of voice (for example, talks like a robot or like he or she is giving a lecture)	☐	☐	☐	☐
bbb) Seems to react to people as if they are objects	☐	☐	☐	☐
ccc) Knows when he or she is too close to someone or is invading someone's space	☐	☐	☐	☐
ddd) Walks in between two people who are talking	☐	☐	☐	☐
eee) Gets teased a lot	☐	☐	☐	☐
fff) Concentrates too much on parts of things rather than seeing the whole picture. For example, if asked to describe what happened in a story, he or she may talk only about the kind of clothes the characters were wearing	☐	☐	☐	☐
ggg) Is overly suspicious	☐	☐	☐	☐
hhh) Is emotionally distant, doesn't show his or her feelings	☐	☐	☐	☐
iii) Is inflexible, has a hard time changing his or her mind	☐	☐	☐	☐
jjj) Gives unusual or illogical reasons for doing things	☐	☐	☐	☐
kkk) Touches others in an unusual way (for example, he or she may touch someone just to make contact and then walk away without saying anything)	☐	☐	☐	☐
lll) Is too tense in social settings	☐	☐	☐	☐
mmm) Stares or gazes off into space	☐	☐	☐	☐

F7. During the **past two weeks**:

a) How worried was your child?

- ☐ Not worried at all
- ☐ Slightly worried
- ☐ Moderately worried
- ☐ Very worried
- ☐ Extremely worried

b) How happy or sad was your child?

- ☐ Very sad/depressed/unhappy
- ☐ Moderately sad/depressed/unhappy
- ☐ Neutral
- ☐ Moderately happy/cheerful
- ☐ Very happy/cheerful

c) How relaxed versus anxious was your child?

- ☐ Very relaxed/calm
- ☐ Moderately relaxed/calm
- ☐ Neutral
- ☐ Moderately nervous/anxious
- ☐ Very nervous/anxious

d) How fidgety/restless was your child?

- ☐ Not fidgety/restless at all
- ☐ Slightly fidgety/restless
- ☐ Moderately fidgety/restless
- ☐ Very fidgety/restless
- ☐ Extremely fidgety/restless

e) How fatigued or tired was your child?

- ☐ Not fatigued or tired at all
- ☐ Slightly fatigued or tired
- ☐ Moderately fatigued or tired
- ☐ Very fatigued or tired
- ☐ Extremely fatigued or tired

f) How well was your child able to concentrate or focus?

- ☐ Very focused/attentive
- ☐ Moderately focused/attentive
- ☐ Neutral
- ☐ Moderately unfocused/distracted
- ☐ Very unfocused/distracted

g) How irritable or easily angered was your child?

- ☐ Not irritable or easily angered at all
- ☐ Slightly irritable or easily angered
- ☐ Moderately irritable or easily angered
- ☐ Very irritable or easily angered
- ☐ Extremely irritable or easily angered

h) How lonely was your child?

- ☐ Not lonely at all
- ☐ Slightly lonely
- ☐ Moderately lonely
- ☐ Very lonely
- ☐ Extremely lonely

SECTION G - YOUR WELLBEING

G1. Families sometimes have special concerns or difficulties because of their child's health. Below 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	☐	☐	☐	☐	☐
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	☐	☐	☐	☐	☐

G1 continued...	Never	Almost never	Some-times	Often	Almost always
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 **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	☐	☐	☐	☐	☐

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... (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?	☐	☐	☐	☐	☐	☐
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	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?	☐	☐	☐	☐	☐	☐

G4. These questions ask you about **<u>your</u>** feelings and thoughts **<u>during the last month.</u>**

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

G4. Continued...

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

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

G4. Continued...

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 program

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

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

G5. These questions ask you about **your** feelings and thoughts **during the last month**.
In each case, you will be asked to indicate *how often* you felt or thought a certain way.

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

G6a. How noticeable do you think your child's cleft is to other people?

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

G6b. 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)	☐	☐	☐	☐	☐

G7. How many close friends do **you** (not your child) have (other than your partner if applicable)?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 or more

G8. Overall, how would you rate your relationships with your close friends?

☐ Poor ☐ Fair ☐ Good ☐ Excellent

G9. These questions ask about your relationship with your current partner (if applicable).

☐ I do not currently have a partner	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	☐	☐	☐	☐	☐

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 or GP who can help.

■SECTION H - ADDITIONAL QUESTIONS FOR THE MOTHER

H1a. Does the child's biological father currently live with you? ☐Yes ☐No

If No, b) How old was your child when the biological father left the home?

	Years	Months	Weeks
i)	☐☐	☐☐	☐☐

ii) Biological father never lived at home / left the home before child was born ☐

H2a. 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

H3a. 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:

☐ Child's biological mother

☐ Someone else (please specify below)

Z2. Do you live in the same house as your 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 ☐

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

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