

You and Your Child at 10 years

Mother's questionnaire

This questionnaire is for the child's mother.

■ 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. **The Wellbeing of You and Your Child** - The last section asks about how you have been feeling recently and your child's development and wellbeing

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 who can help.

Thank you for completing this questionnaire!

SECTION A - YOUR CHILD'S HEALTH

A1. What is your child's gender? Male Female

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

Lbs Oz Kg

--	--	--	--	--	--	--	--	--	--

OR

--	--	--	--	--	--

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

Feet Inches M Cm

--	--	--	--	--	--	--	--

OR

--	--	--	--	--	--

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

Inches Cm Mm

--	--	--	--	--

OR

--	--	--	--	--

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

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. Has your child had any other surgery relating to their cleft lip / cleft palate?
(Cross all that apply)

- a) Grommets b) Bone graft c) Speech surgery
 d) Palate re-repair e) Lip revision f) Fistula repair
 g) Other (please specify) h) None of the above

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A9. Has your child had any of the following infections? **(Cross all that apply)**

- | | |
|--|---|
| <input type="checkbox"/> 0) None | <input type="checkbox"/> i) German measles / Rubella |
| <input type="checkbox"/> ii) Measles | <input type="checkbox"/> iii) Chickenpox |
| <input type="checkbox"/> iv) Mumps | <input type="checkbox"/> v) Meningitis |
| <input type="checkbox"/> vi) Urinary tract infection (E.g. cystitis) | <input type="checkbox"/> vii) Chest infections / pneumonia |
| <input type="checkbox"/> viii) Recurrent ear infections | <input type="checkbox"/> ix) Other infection (please specify) |

A10. Has your child had / does your child have any of the following conditions or problems? **(Cross all that apply)**

a) Neurological / Sensory Conditions

- | | |
|---|---|
| <input type="checkbox"/> 0) None | <input type="checkbox"/> i) Epilepsy / Fits / Convulsions |
| <input type="checkbox"/> ii) Cerebral Palsy | <input type="checkbox"/> iii) Developmental delay |
| <input type="checkbox"/> iv) Hearing loss or impairment | <input type="checkbox"/> v) Glue Ear, OME (Otitis Media with Effusion) |
| <input type="checkbox"/> vi) Difficulties with vision / blindness | <input type="checkbox"/> vii) Other neurological condition (please specify) |

b) Heart / Lungs / Immune system

- | | |
|---|---|
| <input type="checkbox"/> 0) None | <input type="checkbox"/> i) Heart condition |
| <input type="checkbox"/> ii) Lung condition | <input type="checkbox"/> iii) Asthma / Difficulties breathing |
| <input type="checkbox"/> iv) Allergies | <input type="checkbox"/> v) Immune deficiency |
| <input type="checkbox"/> vi) Other problems with heart / lungs/
immune system (please specify) | |

c) Skin / Musculoskeletal conditions

- | | |
|---|--|
| <input type="checkbox"/> 0) None | <input type="checkbox"/> i) Skin condition |
| <input type="checkbox"/> ii) Skeletal condition | <input type="checkbox"/> iii) Talipes (Club foot) |
| <input type="checkbox"/> iv) Spine condition | <input type="checkbox"/> v) Other skin / musculoskeletal
condition (please specify) |

d) Metabolic conditions

- | | |
|---|---|
| <input type="checkbox"/> 0) None | <input type="checkbox"/> i) Thyroid condition |
| <input type="checkbox"/> ii) Abnormal calcium levels | <input type="checkbox"/> iii) Blood condition |
| <input type="checkbox"/> iv) Other metabolic condition (please specify) | |



e) Abdominal conditions

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

f) Kidney and bladder problems

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

A11. 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)
- j) None of the above



A12. 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)
- j) We are currently undergoing genetic testing at the hospital
- k) None

A13. 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)
- j) None

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

- 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) Chronic Fatigue Syndrome (CFS)/ME
- x) Other (please specify)
- xi) None

A14. b) If you answered yes to question A14. a) x), please tell us more in the box below.

A15. Has your child been diagnosed with any other condition not mentioned above?
(please specify below)

For A16, if you have more than one child with these conditions, please make a note in the comments at the back of the questionnaire.





A16. 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 also give their date of birth)

i) You **ii) Child's father** **iii) Other child** **iv) Other child's DOB (if applicable) in 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) / /

k) No





A17. Does your child have a regular sleeping routine? Yes No

A18. How often during the night does your child usually wake? times

A19. In the past year has your child regularly:

	No, did not happen	Yes, but did not worry me	Yes, and worried me a bit	Yes, and worried me greatly	Don't know
a) Refused to go to bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Woken very early	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Had difficulty going to sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Had nightmares	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Continued to get up after being put to bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Got up after only a few hours sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



SECTION B - FEEDING YOUR CHILD

B1. Did your child have any nasal regurgitation (food coming down their nose)?

Yes, often Yes, sometimes No

B2. 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

B3. 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

B4. a) Since your child was 6 months old, have they at any time:

	Yes, and worried me greatly	Yes, and worried me a bit	Some- times	Almost never
i) Not eaten a sufficient amount of food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ii) Refused to eat the right food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
iii) Been choosy with food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
iv) Overeaten	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
v) Been difficult to get into an eating routine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

B5. a) Up to the age of **3 years**, did your child have difficulties with particular tastes or textures? Yes No **If no, go to question B6**

If Yes b) please specify

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

■

B6. When did your child first begin drinking from a cup or a beaker?

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Months

B7. 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)

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B8. 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)

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B9. 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)

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B10. 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)

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B11. Does your child eat the same foods as the rest of the family?

- Usually Sometimes No



B12. Does your child have snacks in the day, between meals?

- No Once Twice More than twice

B13. Now that your child is 10 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 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?

Morning Evening Morning and Evening

Never Other (please specify)

C6. Do you help your child with brushing?

Never Sometimes Always

C7. What toothpaste is your child using?

None Children's toothpaste
(over 3 years)

Adult toothpaste Other (please specify)

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

C9. 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



C10. Does your child eat in the last hour before bed? Yes No

C11. Do you regularly see a family dentist? (Approximately every 6 months)

Yes No

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

Years		Months	
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

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

C16. If you have other children without cleft have you received different advice about tooth brushing for your child born with a cleft?

Yes No Not applicable

C17. 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

C18. a) Do you like the way your child's teeth look now? Yes No

If no b) What don't you like about them? (**Cross all that apply**)

i) Gaps between teeth ii) Crooked iii) Too small

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

vii) Blotchy viii) Other (please specify)

<input type="text"/>

C19. a) Has your child had an orthodontic assessment by the Cleft Team Orthodontist? Yes No **If no, go to question C20**

If yes b) How old was your child at the first orthodontic assessment?

Years		Months	
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

c) If the assessment was carried out by a team, who did it include?

(Cross all that apply)

i) Paediatric dentist ii) Orthodontist iii) Surgeon

d) Where were the orthodontics mainly carried out?

Your main cleft centre Your local hospital Don't know

Other (please specify)

e) Were you advised that orthodontic treatment was necessary?

Yes No

f) 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

g) 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

C20. a) Has your child attended a specific Bone Graft Clinic?

Yes No **If no, go to question C21**

If yes b) Were you advised that a bone graft was required?

Yes No **If no, go to question C21**



c) Did your child require orthodontic/brace treatment prior to the alveolar bone graft?

Yes No

d) Approximately how long did the treatment take before the bone graft?

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

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

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 Days Not applicable

f) Were there any complications with the graft?

Yes No Not applicable

C21. a) Is your child wearing or has your child worn braces? (**Cross all that apply**)

Yes, fixed braces (train tracks) Yes, removable braces
 None

b) How long after the operation (if applicable) were the braces removed?

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

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.

The following questions ask about who has regularly looked after your child since they were 8 years old (**Cross all that apply**)

D1. 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?	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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Other relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Friend or neighbour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Paid person outside the home (e.g. child-minder)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Paid person inside the home (e.g. nanny /babysitter)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) After school club	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Other (please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

D2. What type of school does your child attend?

- Primary school Special school
 Private or independent primary school Other (please specify)



D3. a) 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)

D4. Has your child been given a Statement of Special Educational Needs (SEN) or an Education, Health and Care (EHC) plan?

- Yes, my child has a Statement/EHC plan No, but my child is being assessed
 No, my child was refused a Statement/EHC plan No, my child has never been considered for a Statement/EHC plan

D5. 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

D6. 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

D7. a) Has your child ever received speech and language therapy? (**Cross all 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 all that apply**)

i) Yes, from the cleft team

ii) Yes, at school

iii) Yes, other (please specify)

iv) No

D8. 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

D9. How do you think your child feels about school?

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

D10. 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 F1

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



SECTION F - YOUR LIFESTYLE

- F1. Do you currently drink alcohol? Yes (**Go to question F2**)
 No (**Go to question F3**)

Please use the image below to help you answer question F2



- F2. On average, how many units of alcohol do you drink **per week**?
- | | |
|---|---|
| <input type="checkbox"/> None | <input type="checkbox"/> One to two units |
| <input type="checkbox"/> Three to five units | <input type="checkbox"/> Five to ten units |
| <input type="checkbox"/> Ten to twenty units | <input type="checkbox"/> Twenty to thirty units |
| <input type="checkbox"/> More than thirty units | |
- F3. Do you currently smoke cigarettes? Yes (**Go to question F4**)
 No (**Go to question F5**)
- F4. On average, how many cigarettes do you currently smoke **per day**?
- | | |
|---|--|
| <input type="checkbox"/> Less than one per day | <input type="checkbox"/> One pack (15-24 per day) |
| <input type="checkbox"/> One per day | <input type="checkbox"/> One & ½ packs (25-34 per day) |
| <input type="checkbox"/> Two to four per day | <input type="checkbox"/> Two packs (35-44 per day) |
| <input type="checkbox"/> ½ a pack (5 to 14 per day) | <input type="checkbox"/> More than two packs per day |



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

No (**Go to question F7**)

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

Less than one hour per day

Three to four hours per day

One to two hours per day

More than four hours per day

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

If yes b) How often do you use these substances? (**Cross 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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ii) Cocaine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
iii) Ecstasy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
iv) Amphetamine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
v) Heroin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
vi) Other (specify below)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

i) Vigorous exercise (breathing hard, heart beats rapidly).

For example: running, aerobics, martial arts, fast swimming, or a team sport such as football or hockey

minutes per week

ii) Moderate exercise (heart rate increases slightly, but is not exhausting).

For example: fast walking or gentle cycling

minutes per week

iii) Muscle strengthening activities

For example: lifting weights, push-ups and sit-ups, heavy gardening or yoga

times per week

SECTION G - THE WELLBEING OF YOU AND YOUR CHILD

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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I feel tired when I wake up in the morning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I feel too tired to do the things I like to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I get headaches	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) I feel physically weak	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) I feel sick to my stomach	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) I feel anxious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) I feel sad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) I feel angry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) I feel frustrated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) I feel helpless or hopeless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) I feel isolated from others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) I have trouble getting support from others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n) It is hard to find time for social activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o) I do not have enough energy for social activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>





G1 continued...

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



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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Difficulty finding time to finish household tasks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Feeling too tired to finish household tasks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Lack of communication between family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Conflicts between family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Difficulty making decisions together as a family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Difficulty solving family problems together	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Stress or tension between family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) How much information was provided to you about the treatment and course of your child's health condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) How much information was provided to you about the side effects of your child's treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



G3 continued...

How happy are you with...

Never Some- Often Almost Always N/A
times always

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?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o) How well the staff respond to your child's needs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p) Efforts to keep your child comfortable and as pain-free as possible?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q) How much time the staff take to help you with your child coming back home after hospitalisation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r) The amount of time given to your child to play, talk about her/his feelings, and any questions she/he may have?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
s) The amount of time spent helping your child with going back to school after hospitalisation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
t) The amount of time spent attending to your child's emotional needs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
u) The amount of time spent attending to your emotional needs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
v) The overall care your child is receiving?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
w) How friendly and helpful the staff are?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
x) The way your child is treated at the hospital?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



G4. 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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Restless, overactive, cannot stay still for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Often complains of headaches, stomach-aches or sickness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Shares readily with other children (treats, toys, pencils etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Often has temper tantrums or hot tempers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Rather solitary, tends to play alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Generally obedient, usually does what adults request	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Many worries, often seems worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Helpful if someone is hurt, upset or feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) Constantly fidgeting or squirming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) Has at least one good friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

G4 continued...

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





G5. 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 G7**

G6. **If you have answered "yes" to G5**, 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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ii) Friendships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
iii) Classroom learning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
iv) Leisure activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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



G7. 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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Didn't enjoy anything at all	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Felt so tired that he/she just sat around and did nothing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Was very restless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Felt like he/she was no good anymore	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Cried a lot	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Found it hard to think properly or concentrate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Hated him/herself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Felt he/she was a bad person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) Felt lonely	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) Thought nobody really loved him/her	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) Thought he/she could never be as good as other kids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) Felt he/she did everything wrong	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please contact your Doctor if you have any concerns.



G8. 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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) My child gets headaches when they are at school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) My child doesn't like to be with people they don't know well	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) My child gets scared if they sleep away from home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) My child worries about other people liking them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) When my child gets frightened, they feel like passing out	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) My child is nervous	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) My child follows me wherever I go	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) People tell me that my child looks nervous	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) My child feels nervous with people they don't know well	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) My child gets stomach-aches at school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) When my child gets frightened, they feel like they are going crazy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) My child worries about sleeping alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n) My child worries about being as good as other kids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o) When my child gets frightened, they feel like things are not real	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

■ G8 continued...

	Not true or hardly ever true	Somewhat true or Sometimes true	Very true or often true
p) My child has nightmares about something bad happening to their parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q) My child worries about going to school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r) When my child gets frightened, their heart beats fast	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
s) They get shaky	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
t) My child has nightmares about something bad happening to them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
u) My child worries about things working out for them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
v) When my child gets frightened, they sweat a lot	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
w) My child is a worrier	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
x) My child gets really frightened for no reason at all	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
y) My child is afraid to be alone in the house	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
z) It is hard for my child to talk with people they don't know well	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
aa) When my child gets frightened, they feel like they are choking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
bb) People tell me that my child worries too much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
cc) My child doesn't like to be away from their family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
dd) My child is afraid of having anxiety (or panic) attacks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ee) My child worries that something bad might happen to their parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ff) My child feels shy with people they don't know well	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



G8 continued...

	Not true or hardly ever true	Somewhat true or Sometimes true	Very true or often true
gg) My child worries about what is going to happen in the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
hh) When my child gets frightened, they feel like throwing up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ii) My child worries about how well they do things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
jj) My child is scared to go to school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
kk) My child worries about things that have already happened	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ll) When my child gets frightened, they feel dizzy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
oo) My child is shy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

G9. We are asking these questions to help us understand more about communication strengths and difficulties in children.

My child...	Less than once a week	At least once a week	Once or twice a day	Several times a day
a) Simplifies words by leaving out some sounds, e.g. "crocodile" pronounced as "cockodile", or "stranger" as "staynger"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Pronounces words in a babyish way, such as "chimbley" for "chimney" or "bokkle" for "bottle"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Leaves off beginnings or ends of words, e.g. says "roe" instead of "road" or "nana" instead of "banana"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Makes mistakes in pronouncing long words; e.g. says "vegebable" rather than "vegetable" or "trellistope" rather than "telescope"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Mispronounces "th" for "s" or "w" for "r". E.g. says "thoap" instead of "soap" or "wabbit" instead of "rabbit"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Speaks clearly so that words can be easily understood by someone who doesn't know him/her very well	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Speaks fluently and clearly, producing all speech sounds accurately and without hesitation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Gets mixed up between he and she so might say "he" when talking about a girl, or "she" when talking about a boy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>





G9 continued...

My child...	Less than once a week	At least once a week	Once or twice a day	Several times a day
i) Gets mixed up between he/him or she/her, so might say "him is working" rather than "he is working", or "her have a cake" rather than "she has a cake"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) Produces utterances that sound babyish because they are just 2 or 3 words long, such as "me got ball" instead of "I've got a ball" or "give dolly" instead of "give me the dolly"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) Leaves off past tense -ed endings on words, so might say "John kick the ball" instead of "John kicked the ball", or "Sally play over there" instead of "Sally played over there"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) Leaves out "is" and so says "Daddy going to work" rather than "Daddy's going to work" or "Daddy is going to work". Or might say "The boy big" rather than "The boy is big"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) Produces long and complicated sentences such as: "When we went to the park I had a go on the swings"; "I saw this man standing on the corner"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n) Produces sentences containing "because" such as "John had a cake because it was his birthday"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



■ G9 continued...

My child...	Less than once a week	At least once a week	Once or twice a day	Several times a day
o) Makes false starts, and appears to grope for the right words; e.g. might say "can I - can I - can I - can I have an ice cream"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p) Forgets words he/she knows e.g. instead of "rhinoceros" may say "you know the animal with the horn on its nose"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q) Mixes up words of similar meaning e.g. might say "dog" for "fox", or "screwdriver" for "hammer"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r) Mixes up words that sound similar e.g. might say "telephone" for "television" or "magician" for "musician"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
s) Is vague in choice of words, making it unclear what he/she is talking about, e.g. saying "that thing" rather than "kettle"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
t) Uses abstract words that refer to general concepts rather than something you can see, e.g. "knowledge", "politics", "courage"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
u) Uses words that refer to whole classes of objects, rather than a specific item, e.g. refers to a table, chair and drawers as "furniture", or to apples, bananas and pears as "fruit"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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G10. 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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ii) I worry that the cleft is affecting my relationship with my child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
iii) I worry about the impact of the cleft on my child's learning at school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
iv) I worry about the impact of the cleft on my child's self-confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
v) I worry about the impact of the cleft on my child's ability to get on with other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
vi) I worry about any other treatment that my child might need	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
vii) I feel comfortable talking to my child about their cleft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
viii) My child is able to explain to other people about their cleft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ix) I feel optimistic about my child's future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
x) I feel that there are positives to having a child with a cleft (please specify below)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



G11. How many close friends do **you** (not your child) have (other than your partner if applicable)?

- 0 1 2 3 4 or more

G12. Overall, how would you rate your relationships with your close friends?

- Poor Fair Good Excellent

G13. 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 all 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



G13 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

G14. 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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) My partner and I have problems in our relationship	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I am very happy in my relationship	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) My partner is usually understanding	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) I often think about ending our relationship	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) I am satisfied with my relationship with my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) We often disagree about important decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) I have been lucky in my choice of a partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) We agree about how children should be raised	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) I think my partner is satisfied with our relationship	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



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.

G15. Since your child's cleft was diagnosed, have you received any support from CLAPA?

- Yes No **If no, go to section H**

G16. 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) Emotional support
 d) I have attended a family event
 e) My child has attended an event
 f) I have volunteered/fundraised for CLAPA
 g) My child has volunteered/fundraised for CLAPA
 h) Other (specify below)

G17. How often have you been satisfied with the support you have received from CLAPA?

- Never Sometimes Often
 Almost always Always

G18. 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 your child when the biological father left the home?

	Years		Months		Weeks	
i)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

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 your child? Yes No

Z3. On what date did you complete this questionnaire?

DD	MM	YYYY
<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>

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

DD	MM	YYYY
<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>

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

DD	MM	YYYY
<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>

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

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



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