

# You and Your Child at 18 months

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

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

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





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

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

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

## **How to fill in this questionnaire**

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



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



then cross the correct box.

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

## **Who to contact for support**

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

**Thank you for completing this questionnaire!**





## SECTION A - YOUR CHILD'S HEALTH

A1. How many weeks pregnant were you when you gave birth?

Weeks

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

**The answers to questions A3 to A7 may be found in your child's red book (if available)**

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

Lbs

--	--

Oz

--	--

OR

Kg

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

Lbs

--	--

Oz

--	--

OR

Kg

--	--

--	--

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

Feet

--

Inches

--	--

OR

Cm

--	--

Mm

--

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

Feet

--

Inches

--	--

OR

Cm

--	--

Mm

--

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

Inches

--	--

OR

Cm

--	--

Mm

--

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

Inches

--	--

OR

Cm

--	--

Mm

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

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

A10. If your child has a cleft lip; lip/palate, is it unilateral (on one side of their mouth) or bilateral (on both sides of their mouth)?

- Unilateral     Bilateral     Don't know     Not applicable

A11. If your child's cleft is unilateral (on one side of their mouth), which side of your child's mouth is the cleft on (**when looking at your child**)?

- Right     Left     Don't know     Not applicable

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

- At the 20 week scan     During a 3D scan     At birth     Not applicable

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

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 Weeks     Not applicable

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

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

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

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 Weeks     Not applicable

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

Years	Weeks	Days

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

- Yes     No     Not applicable

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

Months	Weeks

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

Yes  No  Not applicable

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

Months

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A16. Has your child had any other surgery relating to their cleft lip / cleft palate (e.g. hearing, grommets?)

a)  Yes  No **If yes** b) Please specify

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A17. Has your child had any of the following infections? (**Cross all that apply**)

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

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A18. 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"/> iv) Hearing loss or impairment                    |
| <input type="checkbox"/> i) Epilepsy / Fits / Convulsions | <input type="checkbox"/> v) Glue Ear, OME (Otitis Media with Effusion)     |
| <input type="checkbox"/> ii) Cerebral Palsy               | <input type="checkbox"/> vi) Difficulties with vision / blindness          |
| <input type="checkbox"/> iii) Development delay           | <input type="checkbox"/> vii) Other neurological condition (specify below) |

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**b) Heart / Lungs / Immune system**

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

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**c) Skin / Musculoskeletal conditions**

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

**d) Metabolic conditions**

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

**e) Abdominal conditions**

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

**f) Kidney and bladder problems**

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

A19. Does your child have problems with the development of any of the following?

**(Cross all that apply)**

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

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A20. Has **your child** been diagnosed with any of the following syndromes / genetic conditions? (**Cross all that apply**)

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







A21. Have **you, the child's biological father, or any of your other children** been diagnosed with any of the following conditions? (For other children, please give their date of birth)

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



## SECTION B - FEEDING YOUR CHILD

Babies who are born with a cleft often have difficulties feeding. Some parents are able to feed their baby directly from the breast, while other parents need to express breast milk, or use formula milk to help their baby feed

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

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

If yes b) How long did you breast feed your child?

- i)   weeks      ii)  My child is still being fed on breast milk

c) If no, how did you initially feed your child?

- MAM soft bottle (squeeze bottle)       With a normal feeding bottle or teat  
 Haberman feeder bottle system       Other (please specify below)

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

- Breast milk only (including feeding directly from the breast and expressed breast milk)  
 Formula milk only  
 A combination of breast milk and formula milk

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

- Yes, great difficulty       Yes, some difficulty       No difficulties



**If yes** b) Did you find these difficulties upsetting?

- Very upsetting       A little upsetting       No

B4. Did your child initially require any of the following?

- Feeding assistance with a feeding tube (Nasogastric Intubation, NGT)  
 Respiratory assistance due to a blocked airway (Nasopharyngeal Airway, NPA)  
 No assistance

B5. Has your child had any nasal regurgitation (food coming down their nose)?

- Often     Sometimes     No

B6. Has your child had any difficulties swallowing?

- Often     Sometimes     No

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

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 months

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

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 months

B9. Approximately how old was your child when they were first given sweet solids to eat (e.g. sweet baby food in a jar, packet or tin, or homemade e.g. rice pudding, pureed fruits)?

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 months

B10. Since your child was 6 months old, have they at any time:

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

B11. Does your child have difficulties with particular tastes or textures?

a)  Yes  No

If yes b) Please specify

B12. a) Does your child want to feed themselves?

Yes  No

If yes b) How do they feed themselves?

Spoon or fork  Fingers  Both

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

- a) Water  d) Squash  
 b) Milk  e) Other (please specify)  
 c) Fruit juice

B14. What does your child usually drink from?

A bottle  A cup or beaker  Both



B15. If applicable, when did your child first begin drinking from a cup or a beaker?

i)   months    ii)  Not applicable

B16. a) Where does your child normally eat their meals? (**Cross all that apply**)

i) At the table     iii) Walking around  
 ii) In a highchair     iv) Other (please specify)

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

B17. Does your child normally eat... (**Cross all that apply**)

i) Alone     iii) With the whole of the family  
 ii) With siblings     iv) Other (please specify)

B18. Does your child eat the same foods as the rest of the family?

Usually     Sometimes     No

B19. Does your child have snacks in the day, between meals?

No     Once     Twice     More than twice

B20. Now that your child is 18 months of age, do you have any concerns about their eating habits?

a)  Yes     No

**If yes**  
b) please  
specify

## SECTION C - YOUR CHILD'S TEETH

C1. How old was your child when they developed their first tooth?

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 months

C2. How many teeth does your child have now?

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C3. a) Do you brush your child's teeth?  Yes  No

**If yes** b) When?

Morning

Evening

Morning and evening  Other (please specify)

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C4. What toothpaste is your child using?

None

Children's paste (over 3 years)

Children's paste (0-3 years)

Adult toothpaste

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

Yes  No

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

i) Water

iii) Juice

ii) Milk

iv) Other (please specify)

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

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

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

i) Water  iii) Juice

ii) Milk  iv) Other (please specify)

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C7. Do you have a family dentist?  Yes  No

C8. Has your child come with you to the dentist?  Yes  No  Not applicable





C9. Did the dentist look in your child's mouth?  Yes  No  Not applicable

C10. Did the dentist talk to you about caring for your child's teeth?

Yes  No  Not applicable

C11. Did the dentist place fluoride varnish on your child's teeth?

Yes  No  Don't know  Not applicable

C12. a) Has your child seen another dental specialist besides your family dentist?

Yes  No

**If yes** b) Where?

In the cleft team

At the hospital

Somewhere else (please specify)

C13. Has your child been told they have dental caries / decay?

Yes  No  Don't know

C14. Do you have any concerns about your child's teeth? (**Cross all that apply**)

a) Number of teeth

d) Colour of teeth

b) Shape of teeth

e) No concerns

c) Position of teeth

f) Other (specify below)



## SECTION D - ADDITIONAL QUESTIONS ABOUT YOUR CHILD

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

a) When they went down for the night?

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

b) When they woke up?

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

D2. The following questions ask you about who looks after your child (apart from yourself and your partner). **(Cross all that apply)**

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





D3. Generally, does your child listen to people or things that happen nearby?

- Usually     Sometimes     Don't know  
 Often     Usually not

D4. Does your child turn their head towards sounds?

- Usually     Only to very loud sounds     Don't know  
 Sometimes     Never

D5. During or after a cold, is your child's hearing worse than usual?

- Much worse     About the same  
 A little worse     Don't know

D6. Does your child pull, scratch or poke at their ears?

- Quite often     Only when ill, restless or in pain     Don't know  
 Sometimes     Hardly ever

D7. Has pus or sticky mucus (not ear wax) ever leaked out of your child's ears?

- Never     Once     More than once     Don't know

D8. Does your child breathe through their mouth rather than through their nose?

- All the time     Sometimes     Don't know  
 Much of the time     Hardly ever

D9. When children are first learning to communicate, they often use gestures to make their wishes known. Which of the following gestures does your child use?

	i) Not yet	ii) Some times	iii) Often
a) Extends arm to show you something they are holding	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Reaches out and gives you an object they are holding	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Points (with arm and index finger extended) at some interesting object or event	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Waves goodbye on their own when someone leaves	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Extends their arms upwards to signal a wish to be picked up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Shakes head 'no'	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Nods head 'yes'	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Gestures 'hush' by placing finger to lips	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Asks for something by opening and closing hand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) Blows kisses from a distance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

D10. Has your child been involved in any other research studies?

Yes  No  Don't know

**If you answered 'no' or 'don't know' to D10, please go to section E.**

D11. a) Was/is your child involved in the study, 'Timing Of Palatal Surgery (TOPS)?

Yes  No

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

6 months  9 months  12 months

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

Yes  No



D11 continued...



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

- 'Watch and Discover' group (children were videoed at regular intervals and met with researchers for feedback)
- The 'Supported Information and Advice' group

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



## SECTION E - YOUR FAMILY

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

If yes b) What is their date of birth? 

DD			/	MM			/	YY		
----	--	--	---	----	--	--	---	----	--	--

If yes c) What is their gender?  Male  Female

If twins d) What is the gender of the other twin?  Male  Female

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

Yes  No  I have no other children

**If yes, please give us the following information**

**If no, please go to question E3**

### b) Child 1

i) Date of birth 

DD			/	MM			/	YY		
----	--	--	---	----	--	--	---	----	--	--

ii) Gender?

- Male  
 Female

iii) What is their cleft type?

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

iv) Is their cleft:

- Unilateral  
 Bilateral  
 Not known

### c) Child 2

i) Date of birth 

DD			/	MM			/	YY		
----	--	--	---	----	--	--	---	----	--	--

ii) Gender?

- Male  
 Female

iii) What is their cleft type?

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

iv) Is their cleft:

- Unilateral  
 Bilateral  
 Not known



E3. a) Are any of your other children enrolled in this study?  Yes  Not applicable  
 No

If yes b) What is their date of birth? DD MM YY  
[ ][ ] / [ ][ ] / [ ][ ]

If yes c) What is their gender?  Male  Female

E4. a) Please tell us who lives in your current household? (Cross all that apply)

- i) Your spouse or domestic partner
- ii) Your children or stepchildren
- iii) Your siblings
- iv) Your parents
- v) Other relatives (please specify) [ ]
- vi) Unrelated individuals (please specify) [ ]
- vii) Live alone

b) Please tell us the following

- i) Number of children/stepchildren who live with you [ ][ ]
- ii) Number of siblings who live with you [ ][ ]
- iii) Number of parents who live with you [ ][ ]
- iv) Number of other relatives who live with you [ ][ ]
- v) Number of unrelated individuals who live with you [ ][ ]

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

[ ][ ] years AND/OR [ ][ ] months AND/OR [ ][ ] weeks



E6. What is your current marital status?

- Single                       Domestic partner    Married  
 Separated                 Divorced                 Widowed  
 Civil Partnership

E7. How long have you lived in this current marital arrangement?

years   AND/OR     months   AND/OR     weeks

E8. How would you describe your relationship with your current partner (if applicable)?

	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"/>

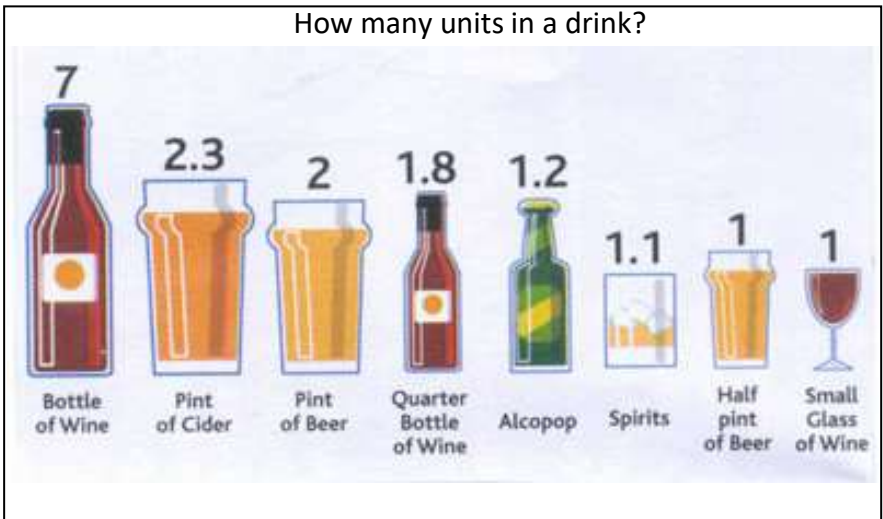


## SECTION F - YOUR LIFESTYLE

F1. Do you currently drink alcohol?  Yes  No

If yes, go to question F2, if no go to question F5.

Please use the image below to help you answer question F2



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

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



F3. On average, how often do you drink alcohol?

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

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

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

F5. Do you currently smoke?  Yes (**Go to question F6**)  
 No (**Go to question F8**)

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

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

F7. Where do you usually smoke?

- Only outside
- Only inside
- Both inside and outside

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





If yes b) How many hours a day are you exposed to passive smoke?

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

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

If yes b) How many hours is your child exposed to passive smoke?

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

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

- a) Nicotine gum
- b) Adhesive patch
- c) Nicotine sprays
- d) Nicotine inhalers
- e) Lozenges or tablets
- f) 'Snus' or nasal snuff
- g) Chewing tobacco
- h) Electronic cigarette
- i) None
- j) Other (please specify)

F11. a) Do you currently use any drugs?  Yes  No

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

	Never	Once a year	Twice a year	Once every two months	Once a month	Twice a month	Once a week or more
i) Cannabis	<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"/>



**Question F12 has been intentionally removed**

F13. During a typical week, how many minutes / times per week on average do you do the following types of exercise?

**a) 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

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

For example: fast walking or gentle cycling

minutes per week

**c) Muscle strengthening activities**

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

times per week

F14. On average, how much time do you spend outdoors?

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



## SECTION G - YOUR WELLBEING

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

- 0     1     2     3     4 or more

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

- Poor     Fair     Good     Excellent

G3. In the last year, did you experience a period of acute stress or an emotional event which had an influence on your state of mind? **(Please cross 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

■

G3 continued...

- xix) Change in number of arguments with spouse
- xx) Setting up a mortgage
- xxi) Foreclosure of mortgage or loan
- xxii) Change in responsibilities at work
- xxiii) Son or daughter leaving home
- xxiv) Trouble with in-laws
- xxv) Outstanding personal achievement
- xxvi) Partner begins or stops work
- xxvii) Begin or end school/higher education
- xxviii) Change in living conditions
- xxix) Change in personal habits
- xxx) Trouble with your boss at work
- xxxi) Change in work hours or conditions
- xxxii) Moving house
- xxxiii) Change in schools/higher education
- xxxiv) Change in hobbies
- xxxv) Change in church activities
- xxxvi) Change in social activities
- xxxvii) Getting a small loan
- xxxviii) Change in sleeping habits
- xxxix) Change in the number of family get-togethers
- xl) Change in eating habits
- xli) Holiday
- xlii) Christmas
- xliii) Minor breaches of the law



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

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

	Never	Almost never	Some-times	Often	Almost always
a) I feel tired during the day	<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"/>



G4 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"/>



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

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

	Never	Almost never	Some-times	Often	Almost Always
a) Family activities taking more time and effort	<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"/>

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

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

**How happy are you with...**

(For example, 'Never happy', 'Often happy' etc)

	Never	Some-times	Often	Almost always	Always	N/A
a) How much information was provided to you about your child's diagnosis?	<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"/>

G6 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?                 





G6 continued...



How happy are you with...	Never	Some- times	Often	Almost always	Always	N/A
n) The preparation provided for <b>your child</b> 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 <b>your child's</b> 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 <b>your</b> 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"/>



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?**

G7. a) Are you happy with the outcome of your child's surgery so far?

- Very happy       Neutral       Very unhappy  
 Quite happy       Quite unhappy

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

- Not at all noticeable     Makes no difference     Very noticeable  
 A little noticeable       Quite noticeable

	Never	Almost never	Some-times	Often	Almost always
c) 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"/>
d) I feel that it is my fault that my child was born with a cleft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) I struggle to come to terms with my child's cleft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) I worry that I am unable to care for my child because of the cleft	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) I worry about other health problems my child may have	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) 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"/>
i) I worry about my child's future cleft treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) I feel optimistic about my child's future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) I feel that there are positives to having a child with a cleft ( <b>please specify below</b> )	<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.

G8. Since your child's cleft was diagnosed, have you received any support from CLAPA?

- Yes  No

**If no, go to question G11.**

**For more information about CLAPA please go to the website; [www.clapa.com](http://www.clapa.com), or contact them by telephone on 020 7833 4883**

G9. What type of support have you received from CLAPA? (**Cross all that apply**)

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

G10. How often have you been satisfied with the support you have received from CLAPA?

- Never  Almost never  Sometimes  Often  Almost always

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.

G11. These questions ask you about your feelings and thoughts **during the last month.**

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



G12. These questions ask you about your feelings and thoughts during the last month.

**a) I feel tense or 'wound up'**

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

**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

**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

**g) I can sit at ease and feel relaxed**

- Definitely
- Usually
- Not often
- 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

**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

**f) I feel cheerful**

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

**h) I feel as if I am slowed down**

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



G12 continued...

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

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

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

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

**m) I get sudden feelings of panic**

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

**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

**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

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

- Often
- Sometimes
- Not often
- Very seldom





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

G13.	Yes	Some- times	Not yet
a) When your child wants something, does he/she tell you by pointing to it?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) When you ask your child to, does he/she go into another room to find a familiar object?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Does your child say eight or more words in addition to 'mama' and 'dada'?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Does your child imitate a two-word sentence? For example, when you say a two-word phrase such as 'mama eat', does your child say both words back to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Without showing him/her, does your child point to the correct picture when you say, 'Show me the cat', or ask, 'Where is the dog?'	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Does your child say two or three words that represent different ideas together, such as 'See dog', or 'mummy come home'?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

G14.	Yes	Some- times	Not yet
a) Does your child bend over or squat to pick up an object from the floor and then stand up again without any support?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Does your child move around by walking, rather than crawling on his/her hands and knees?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Does your child walk well and seldom fall?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Does your child climb on an object such as a chair to reach something he wants (for example, to get a toy on to a counter or to 'help' you in the kitchen?)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Does your child walk down the stairs if you hold onto one of his/her hands? He/she may also hold onto the railing or wall	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) When you show your child how to kick a ball, does he/she try to kick the ball by moving his/her leg forward or by walking into it?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>





	Yes	Some- times	Not yet
G15.			
a) Does your child throw a small ball with a forward arm motion ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Does your child stack a small block or toy on top of another one?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Does your child make a mark on the paper with the tip of a crayon (or pencil or pen) when trying to draw?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Does your child stack three small blocks or toys on top of each other by him/herself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Does your child turn the pages of a book by him/herself? (He/she may turn more than one page at a time)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Does your child get a spoon into his/her mouth right side up so that the food usually doesn't spill?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Yes	Some- times	Not yet
G16.			
a) Does your child drop several small toys, one after another, into a container like a bowl or a box?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) After you have shown your child how, does he/she try to get a small toy that is slightly out of reach by using a spoon, stick, or similar tool?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) After a crumb of food is dropped into a small, clear bottle, does your child turn the bottle over to dump it out? <b>(You may show him/her how)</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Without showing him/her how, does your child scribble back and forth when you give him/her a crayon (or pencil or pen)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) After watching you draw a line from the top of the paper to the bottom with a crayon (or pencil or pen), does your child copy you by drawing a single line on the paper in any direction?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) After a crumb of food is dropped into a small, clear bottle, does your child turn the bottle upside down to dump out the crumb of food? <b>(Do not show him/her how)</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>







G17.	Yes	Some- times	Not yet
a) While looking at him/herself in the mirror, does your child offer a toy to his/her own image?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Does your child play with a doll or stuffed animal by hugging it?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Does your child get your attention or try to show you something by pulling on your hand or clothes?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Does your child come to you when he/she needs help, such as with winding up a toy or unscrewing a lid from a jar?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Does your child drink from a cup or glass, putting it down again with little spilling?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Does your child copy the activities you do, such as wipe up a spill, sweep, shave or comb hair?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

G18. Do you think your child hears well? Yes No

G19. Do you think your child talks like other toddlers his / her age? Yes No

G20. Can you understand most of what your child says? Yes No

G21. Do you think your child walks, runs and climbs like other toddlers his / her age?

Yes No

G22. Does either parent have a family history of childhood deafness or hearing impairment? Yes No



■

G23. a) Do you have concerns about your child's vision?  Yes  No

b) If **yes**, please explain

G24. a) Do you have concerns about your child's behaviour?  Yes  No

b) If **yes**, please explain

**Question G25 has been intentionally removed.**



G26. These questions ask about your child's development. Please cross the box which best describes your child's behaviour. In addition, please cross the final box if this behaviour is a concern to you.

	Most of the time	Some-times	Rarely or never	Cross if this is a concern
a) Does your child look at you when you talk to him/her?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) When you leave, does your child remain upset and cry for more than an hour?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Does your child laugh or smile when you play with him/her?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Does your child look for you when a stranger approaches?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Is your child's body relaxed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Does your child like to be hugged or cuddled?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) When upset, can your child calm down within 15 minutes?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Does your child stiffen and arch his/her back when picked up?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Does your child cry, scream, or have tantrums for long periods of time?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) Is your child interested in things around him/her, such as people, toys and foods?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) Does your child do things over and over and can't seem to stop? Examples include rocking or hand flapping.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) Does your child have eating problems, such as stuffing foods, vomiting or eating non-food items?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) Does your child have trouble falling asleep at naptime or at night?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n) Do you and your child enjoy mealtimes together?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



G26. Continued

	Most of the time	Some-times	Rarely or never	Cross if this is a concern
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o) Does your child sleep at least 10 hours in a 24-hour period?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p) When you point at something, does your child look in the direction you are pointing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q) Does your child get constipated or have diarrhoea?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r) Does your child let you know how he/she is feeling with gestures or words? For example, does he/she let you know when he/she is hungry, hurt or tired?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
s) Does your child follow simple directions? For example, does he/she sit down when asked?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
t) Does your child like to play near or be with family members and friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
u) Does your child check to make sure you are near when exploring new places, such as a park or a friend's home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
v) Does your child like to hear stories or sing songs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
w) Does your child hurt themselves on purpose?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
x) Does your child like to be around other children?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
y) Does your child try to hurt other children, adults, or animals, for example, by kicking or biting?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
z) Has anyone expressed concerns about your child's behaviours? If you cross "sometimes" or "most of the time", please specify in the box below	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>





G27. a) Do you have concerns about your child's eating or sleeping behaviours?

Yes  No

**If yes** b) Please explain

G28. a) Is there anything that worries you about your child?  Yes  No

**If yes** b) Please explain

G29. What things do you enjoy most about your child?





## SECTION H - ADDITIONAL QUESTIONS FOR THE MOTHER

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

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

Months		Weeks	

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
- Don't know

c) Was 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

**Please go to section Z on the back page**



## SECTION Z

Z1. This questionnaire was completed by:

a) Child's biological mother

b) Someone else (please cross box and describe)

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

Z3. On what date did you complete this questionnaire?

DD MM YYYY  
 /  /

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

DD MM YYYY  
 /  /

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

DD MM YYYY  
 /  /

### THANK YOU FOR COMPLETING THIS QUESTIONNAIRE.

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

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

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

Office use only

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