

ID LABEL

# You and Your Child

# Mother's questionnaire 5 Year Old Cohort

# This questionnaire is for the child's mother.









May 2019 - Version 5 (for office use only)

# About this research

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

#### About this questionnaire

This questionnaire has six sections:

- 1. About You this section asks for information such as your ethnicity.
- 2. Work and Education this section asks for information including your educational achievements and your current employment status.
- 3. **Family Life** this section asks you questions about where you live, your marital status and your other children (if applicable).
- 4. Health and Illness this section asks about your family's health history.
- 5. Your Lifestyle this section asks questions about your diet, alcohol use, cigarette smoking and exercise.
- 6. Your Wellbeing the last section asks about how you have been feeling recently.

<u>Please try to answer all of the questions</u>, 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 in 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:

# X

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 refer to the contact details in your starter pack of people who can help.

Thank you for completing this questionnaire!

# **SECTION A - ABOUT YOU**

A1. Please tell us your ethnicity, your mother's ethnicity and your father's ethnicity

a) White	i) You	ii) Your mother	iii) Your father
British			
Irish			
Any other White background			
(please cross box and specify)			
b) Mixed	i) You	ii) Your mother	iii) Your father
White and Black Carib	bean 🗌		
White and Black Africa	in 🗌		
White and Asian			
Any other mixed background			
(please cross			
box and specify)			
c) Asian or Asian Britis	h i) You	ii) Your mother	iii) Your father
Indian			
Pakistani			
Bangladeshi			
Any other Asian background			
(please cross box and specify)			



A1 continued...

d) Black or Black Britis	sh i) You	ii) Your mother	iii) Your father				
Caribbean							
African							
Any other Black background							
(please cross box and specify)							
a) Chinaga ay athay							
e) Chinese or other ethnic group	i) You	ii) Your mother	iii) Your father				
Chinese							
Any other background							
(please cross box and specify)							
· · · ·							
A2. Your country o	f birth:						
A3. How long have in the UK?							
A4. What is your re	What is your religion?						
None	□ None						
	-	f England, Catholic, stian denominations)					
□ Buddhist		······,					
🗆 Hindu							

□ Jewish

🗆 Sikh

 $\Box$  Any other religion (please specify)

A5. How old were you at the time your child was conceived?



A6. If known, how old were YOUR parents at the time YOU were conceived?



Your father

- A7. What is the name of the hospital in which your child received a diagnosis of cleft?
- A8. What is the name of the hospital (or place) in which your child was born (if different to the above)?
- A9. What is the name of the hospital in which your cleft team is based?

#### The following questions ask about your child's cleft

A10. What type of cleft was your child born with?

Cleft lip Cleft palate Cleft lip and palate

Submucous cleft palate Don't know

A11. 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

A12. If your child's cleft is unilateral (on one side of their mouth), which side of your child's mouth is the cleft on <u>(when looking at your child)</u>?

Right	Left	🗌 Don't know	☐Not applicable



## **SECTION B - WORK AND EDUCATION**

B1.	What is the highest educational qualification you have obtained? <b>(Cross <u>one</u> box only)</b>							
	One or more O Levels/CSEs/GCEs (any grades)							
	☐ Five or more O Levels/CSEs (grade 1)/GCSEs (grades A*-C)/School Certificate							
	One or more A Levels/AS Levels							
	🔲 Two or more	A Levels/Four or I	more AS Levels/Hig	gher School Certificate				
	NVQ Level 1/	Foundation GNVC	2					
	NVQ Level 2/	Intermediate GNV	/Q					
	NVQ Level 3/	Advanced GNVQ						
	NVQ Levels 4	-5/HNC/HND						
	🔲 First degree (	e.g. BA/BSc)						
	Higher degree	e (e.g. MA, PhD, p	ostgraduate PGCE	)				
	Other qualific	ations (e.g. City a	nd Guilds, RSA/OC	R, BTEC/Edexcel)				
	Overseas qua	lifications (please	specify)					
	🗌 No qualificati	ons						
	🗌 Don't know							
	Other (please	specifiy)						
B2.	Overall, how wou	uld you rate your s	school experience	2				
	Poor	🗌 Fair	🗌 Good	Excellent				
B3.	Overall, how wou	uld you rate your	school academic p	erformance?				
	Poor	🗌 Fair	🗌 Good	Excellent				
B4.	Overall, how wou	uld you rate your	school enjoyment?					
	Dev Poor	🗌 Fair	🗌 Good	Excellent				
B5.	Overall, how wo	uld you rate your	relationships with	your school teachers?				
	Dev Poor	🗌 Fair	🗌 Good	Excellent				
B6.	Overall, how wou	uld you rate your	relationships with	your school friends?				
	Poor	🗌 Fair	🗌 Good	Excellent				

Fair	🗋 Good	

B7.	a) Have you ever experienced teasir	g and bullying? 🗌 Yes 🔲 No
	b) If yes, how bad do you feel this te	asing and bullying was?
	Not very bad Modera	e 🗌 Very bad
B8.	What is your current employment sta	atus? <b>(Cross <u>one</u> box only)</b>
	🔲 Student	Rehabilitation/disabled
	🗌 Homemaker	Employed in public sector
	Intern/apprentice	Employed in private sector
	Military Service	Self-employed
	Unemployed/laid off	Other (please specify below)
B9.	What is your current/most recent oc See below and on the next page for e	
	Professional/executive	Unskilled worker
	Small business, proprietor, sales	Student/school pupil
	Clerical/administrative	Homemaker
	Skilled worker	Volunteer worker
	Semi-skilled worker	Other (please specify below)

#### **EXAMPLES OF OCCUPATION TYPES**

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

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

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



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

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

**Unskilled worker:** An unskilled worker who has received no special training to do their work.

- B10. What is your current/most recent job title?
- B11. How long have you worked/did you work in your current/most recent job?



months

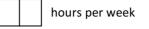
B12. a) In the last year, have you been absent from work for more than two weeks in a row (apart from maternity leave)?

	Yes		No
--	-----	--	----

vears

b) If yes, what was the reason for your absence? (Cross one box only)

B13. On average, how many hours do you currently work per week?



- B14. What are your current working hours? (Cross one box only)
  - Permanent day work
  - Permanent evening work
  - Permanent night work
  - □ Shift work or shift rotations
  - □ No set times (e.g. temporary employment)
  - Other (please specify)
- B15. How do the following statements describe your current work situation?



B16. This table shows income in weekly, monthly and annual amounts. Which of the amounts on this list represents YOUR individual total income from all jobs, tax credits, benefits and other sources after tax when added together? (Cross <u>one</u> box only)

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

B17. Which of these credits/allowances/benefits do **YOU** receive as an individual? (Cross <u>all</u> that apply)

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

B18. Approximately how much of YOUR total individual income comes from benefits?

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



# **SECTION C - FAMILY LIFE**

C1. How long have you lived at your current address?

	years		months
	years		montin

C2. In which of these ways does your household occupy your current address? (Cross <u>one</u> box only)

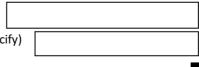
Buying	it	with	the	heln	of a	mortgage	or	loan
Duying	īι	WILLI	uie	neih	UI a	mongage	UI	IUall

Owns	it	outright
------	----	----------

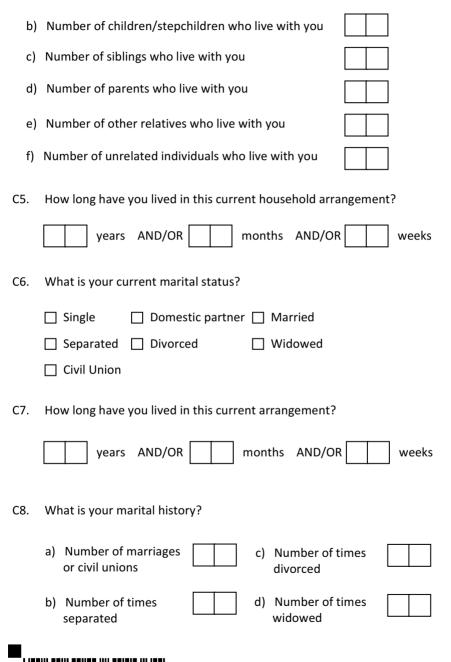
- 🗌 Rents it
- Lives here rent free (e.g. in a relative's or friend's property)
- Pays part rent and part mortgage (shared ownership)
- Don't know
- Other (please specify)
- C3. If you rent your property, live in your property rent free, or pay part rent and part mortgage, please tell us who your landlord is? (**Cross <u>one</u> box only**)
  - □ Private landlord or letting agency
  - Housing Association, Housing Co-Operative, Charitable Trust
  - Local Authority/Council
  - □ Relative or friend
  - Employer
  - Don't know
  - □ Other (please specify)
  - □ Not applicable



- C4. a) Please tell us who lives with you in your current household? (Cross <u>all</u> that apply)
  - □ i) Your spouse or domestic partner
  - ii) Your children/stepchildren
  - iii) Your siblings
  - iv) Your parents
  - v) Other relatives (please specify)
  - □ vi) Unrelated individuals (please specify)



C4 Continued...



C9. How would you describe your relationship with your current partner (if applicable)?

			Agree	Agree Somewhat	Neutral	Disagree Somewhat	Disagree
a)	a close relationship						
b)	My partner and I hat problems in our rela						
c)	relationship	·					
d)	understanding	ly					
,	I often think about ending our relations	-					
	I am satisfied with n relationship with my	/ partner					
	We often disagree a important decisions	;					
	I have been lucky in choice of a partner						
	We agree about how children should be r	aised					
	I think my partner is with our relationship						
C10	<ul> <li>C10. a) Is this your first biological child? Yes No</li> <li>b) Please tell us all of your biological children's date of birth and gender?</li> </ul>						
		ate of Birth	dd/mr	m/yyyy)	Gend	er	
I	) First child (first born)				№	1ale 🗌 Fe	male
i	i) Second child						male
	ii) Third child						emale
	v) Fourth child		/ L / [				emale
``							emale

C11.	a)	Are any of you previous relati	-	children	from a	□ Y	es 🗌 No	
	b)	If yes, please i	ndicate whicl ] ii) Second	h childre				] v) Fifth
C12.	a)	Do you have a	ny stepchildr	en?	🗌 Ye	s 🗌 No		
	b)	lf yes, please t	ell us your st	epchildr	en's da	ate of bir	th and genc	ler:
			Date of Birt	h (dd/m	nm/yyy	/y)	Gender	
		t stepchild est)	/	/			] 🗌 Male	e 🗌 Female
	•	cond stepchild	/	/			] 🗌 Male	e 🗌 Female
iii)	Thi	rd stepchild		/			] 🗌 Male	e 🗌 Female
iv)	Fo	urth stepchild	/	/			] 🗌 Male	e 🗌 Female
v)	Fift	th stepchild	/	/			] 🗌 Male	e 🗌 Female
C13.	WI	hat is your first	language?	Eng	lish [	] Other	(please spec	cify below)

C14. If you speak a language other than English, do you often speak this language in your home?



# SECTION D - HEALTH AND ILLNESS

D1.	Please tell us if <b>YOU</b> were born: At full term
	Prematurely
	🗌 Don't know
D2.	What was <b>YOUR</b> birth weight (if known)?
	Lbs Oz Kg
D3.	a) Are <b>YOU</b> a twin or multiple?
	<ul> <li>b) If yes, are YOU:</li> <li>An identical twin (monozygotic)</li> <li>A non-identical twin (dizygotic)</li> <li>Multiple</li> <li>Don't know</li> </ul>
D4.	a) When <b>YOU</b> were a child, did <b>YOU</b> ever go to a speech and language therapist?
	□ Yes □ No □ Don't know
	b) If yes, please tell us more:

D5. Have **you** or any of your **biological family members** (parents, grandparents, your child born with cleft, siblings, cousins, etc.) been diagnosed by a medical professional with any of the following medical conditions?

		ii) Is there	1
		a family	iii) If yes <i>,</i> who in your
Medical Conditions	i) You	history?	family?
	🗌 Yes	🗌 Yes	
a) Epilepsy or seizures	🗌 No	🗌 No	
	🗌 Yes	🗌 Yes	
b) High blood pressure	🗌 No	🗌 No	
	🗌 Yes	🗌 Yes	
c) Diabetes	🗌 No	🗌 No	
d) the set discourse	🗌 Yes	🗌 Yes	
d) Heart disease	🗌 No	🗌 No	
e) Arthritis	🗌 Yes	🗌 Yes	
	🗌 No	🗌 No	
f) Thyroid condition	🗌 Yes	🗌 Yes	
	🗌 No	🗌 No	
g) Hepatitis	🗌 Yes	🗌 Yes	
	🗌 No	🗌 No	
h) Lupus	🗌 Yes	🗌 Yes	
, i	🗌 No	🗌 No	
i) Severe acne	🗌 Yes	🗌 Yes	
	🗌 No	🗌 No	
j) Asthma	🗌 Yes	🗌 Yes	
	🗌 No	🗌 No	
k) Allergies	🗌 Yes	🗌 Yes	
	🗌 No	🗌 No	
l) Severe headaches	🗌 Yes	🗌 Yes	
	🗌 No	🗌 No	
m) Chronic ear infections	🗌 Yes	🗌 Yes	
	🗌 No	🗌 No	
n) Other medical cond.	🗌 Yes	🗌 Yes	
	No	🗌 No	
o) Other medical cond.	🗌 Yes	🗌 Yes	
	No	🗌 No	



D6. Have **you** or any of your **biological family members** (parents, grandparents, your child born with cleft, siblings, cousins, etc.) been diagnosed by a medical professional with any of the following types of cancer?

		ii) Is there a family	2
Type of Cancer	i) You	history?	iii) If yes, who in your family?
	🗌 Yes	🗌 Yes	
a) Breast	🗌 No	🗌 No	
	🗌 Yes	🗌 Yes	
b) Cervical	🗌 No	🗌 No	
c) Colon and/or	🗌 Yes	🗌 Yes	
rectum	🗌 No	🗌 No	
	🗌 Yes	🗌 Yes	
d) Leukaemia	🗌 No	🗌 No	
N	🗌 Yes	🗌 Yes	
e) Lung	🗌 No	🗌 No	
f) Drestate	🗌 Yes	🗌 Yes	
f) Prostate	🗌 No	🗌 No	
	🗌 Yes	🗌 Yes	
g) Skin	🗌 No	🗌 No	
	🗌 Yes	🗌 Yes	
h) Testicular	🗌 No	🗌 No	
	🗌 Yes	🗌 Yes	
i) Thyroid	🗌 No	🗌 No	
i) Utomuo	🗌 Yes	🗌 Yes	
j) Uterus	🗌 No	🗌 No	
k) Other type of cancer	🗌 Yes	🗌 Yes	
	🗌 No	🗌 No	

D7. Have **you** or any of your **biological family members** (parents, grandparents, your child born with cleft, siblings, cousins, etc.) been diagnosed by a medical professional with any of the following specific health conditions?

Specific Health Condition i) You			ii) Is there a family history?	iii) If yes, who in your family?	
a)	Heart defect	☐ Yes ☐ No	☐ Yes ☐ No		
b)	Short-sightedness	☐ Yes ☐ No	☐ Yes ☐ No		
c)	Learning disability	☐ Yes ☐ No	☐ Yes ☐ No		
d)	Other congenital defect (other than cleft)	□ Yes □ No	☐ Yes ☐ No		
e)	Genetic disorder	☐ Yes ☐ No	Yes No		
f)	Hearing loss or impairment	□ Yes □ No	☐ Yes ☐ No		

- g) If yes to f), please tell us about the type of hearing loss:
  - Temporary (conductive)
  - Permanent (sensorineural)
  - 🗌 Don't know

h) If this hearing loss is permanent, do you/they use hearing aids?

🗌 Yes 🗌 No 📄 Don't know



D8. Have **you** or any of your **biological family members** (parents, grandparents, your child born with cleft, siblings, cousins, etc.) been diagnosed by a medical professional with any of the following mental health conditions?

Me	ental Health Condition	i) You	ii) Is there a family history?	iii) If yes, who in your family?
a)	Behavioural problem iv) Please specify below	☐ Yes ☐ No	□ Yes □ □ No □	
b)	Anxiety .	☐ Yes ☐ No	□ Yes □ No	
c)	Phobia	☐ Yes ☐ No	Yes No	
d)	Depression	☐ Yes ☐ No	□ Yes □ No	
e)	Manic depressive illness (Bipolar)	☐ Yes ☐ No	□ Yes □ No	
f)	Schizophrenia	☐ Yes ☐ No	□ Yes □ No □	
g)	Other iv) Please specify below	☐ Yes ☐ No	□ Yes □ No	

D9.a) Have <b>YC</b>	<b>DU</b> been diagnosed wi	th a cleft lip or palate?	
☐ Nc ☐ Cle			ft palate
	is your cleft unilateral ral (on both sides of yo	l (on one side of your mouth) or our mouth)?	r
🗌 Un	ilateral 🗌 Bilateral	🗌 Don't know	
father and his		<b>ding your other children <u>and</u> y</b> eed with a cleft lip or palate? (If t of birth)	-
a) i) Please tell us	s who in your family?	ii) What was their cleft type?	iii) Was their cleft:
		<ul> <li>Cleft lip</li> <li>Cleft palate</li> <li>Cleft lip and palate</li> <li>Submucous cleft palate</li> <li>Not known</li> </ul>	<ul> <li>Unilateral</li> <li>Bilateral</li> <li>Not known</li> </ul>
b) i) Please tell us	who in your family?	ii) What was their cleft type?	iii) Was their cleft:
		<ul> <li>Cleft lip</li> <li>Cleft palate</li> <li>Cleft lip and palate</li> <li>Submucous cleft palate</li> <li>Not known</li> </ul>	<ul> <li>Unilateral</li> <li>Bilateral</li> <li>Not known</li> </ul>
c) i) Please tell us	who in your family?	ii) What was their cleft type?	iii) Was their cleft:
		<ul> <li>Cleft lip</li> <li>Cleft palate</li> <li>Cleft lip and palate</li> <li>Submucous cleft palate</li> <li>Not known</li> </ul>	<ul> <li>Unilateral</li> <li>Bilateral</li> <li>Not known</li> </ul>
d) i) Please tell us	who in your family?	ii) What was their cleft type?	iii) Was their cleft:
		<ul> <li>Cleft lip</li> <li>Cleft palate</li> <li>Cleft lip and palate</li> <li>Submucous cleft palate</li> <li>Not known</li> </ul>	<ul> <li>Unilateral</li> <li>Bilateral</li> <li>Not known</li> </ul>



D10. Continued...

type? iii) Was their cleft: Unilateral Bilateral Not known late type? iii) Was their cleft:
☐ Bilateral ☐ Not known late
type? :::) Mas their slaft.
was their cleft.
☐ Unilateral ☐ Bilateral ☐ Not known late
□ No
🗌 Yes 🔲 No
🗌 Yes 🔲 No

SECTION E - YOUR LIFESTYLE

E1.	What is your height?	feet inches m cm			
E2.	What is your current weight?	stone lbs kg			
E3.	What is the heaviest you have weighed since you were 16 years old (Excluding pregnancy)?	stone lbs kg			
E4.	What is the lightest you have weighed since you were 16 years old?	stone Ibs kg			
E5.	Have you ever dieted or limited 🛛 Yes 🗌 No your food intake?				
E6.	If yes, how old were you the first time you dieted or limited your food intake?				
E7.	Have you ever used any of thei) Vomitingiv) Hard physical exercisefollowing methods to control yourii) Laxativesv) Medicationweight? (Cross all that apply)iii) Fastingvi) None				
E8.	How would you I have a va describe your general diet? (Cross <u>one</u> box only)	rried diet 🛛 I eat a vegan diet etarian diet 🗍 Other (please specify below)			
E9.	On average, how often do you ea	t fruit and vegetables (including fruit juice)?			

Twice a monthOne to three times a week

□ Never or rarely

24

Four to seven times a week

More than once a day

E10. On average, how often do you eat milk and dairy p yoghurt)?		milk and dairy products (such as cheese and
	Never or rarely	Four to seven times a week
	Twice a month	More than once a day
	One to three times a week	
E11.	On average, how often do you eat eggs and beans)?	protein-rich products (such as meat, fish,
	Never or rarely	Four to seven times a week
	Twice a month	More than once a day
	One to three times a week	
E12.	On average, how often do you eat chocolate, biscuits, cakes and ice	products containing fat and sugar (such as cream)?
	Never or rarely	Four to seven times a week
	Twice a month	More than once a day
	One to three times a week	
E13.	On average, how often do you eat rice, potatoes and pasta)?	starchy products (such as bread,
	Never or rarely	Four to seven times a week
	Twice a month	More than once a day
	One to three times a week	
E14.	On average, how often do you eat wholegrain cereal and bread)?	wholegrain food varieties (such as
	Never or rarely	Four to seven times a week
	Twice a month	More than once a day
	One to three times a week	
E15.	On average, how often do you eat canteens/petrol stations/corner s	meals and sandwiches bought from hops?
	Never or rarely	Four to seven times a week
	Twice a month	More than once a day
	One to three times a week	

E16.	On average, how often do you eat fast-food restaurant?	t foods or meals from a takeaway outlet o
	Never or rarely	Four to seven times a week
	Twice a month	More than once a day
	One to three times a week	
E17.	On average, how often do you eat oven-ready meals)?	t 'ready meals' (such as microwavable or
	Never or rarely	Four to seven times a week
	Twice a month	More than once a day
	One to three times a week	
E18.	On average, how often do you drir	nk caffeinated tea or coffee?
	Never or rarely	Three to five cups a day
	One or two cups a week	More than five cups a day
	One or two cups a day	
E19.	On average, how often do you drin or coffee?	nk herbal tea or decaffeinated tea
	Never or rarely	Three to five cups a day
	🔲 One or two cups a week	More than five cups a day
	One or two cups a day	
E20 (	On average, how often do you drinl	k fizzy drinks (such as coke or lemonade)?
	Never or rarely	Three to five times a day
	One or two times a week	More than five times a day
	One to two times a day	
E21.	On average, how often do you drir	nk energy drinks?
	Never or rarely	Three to five times a day
	One to two times a week	More than five times a day
	One to two times a day	
E22.	On average, how often do you drir	nk water?
	Never or rarely	Three to five times a day
	One to two times a week	More than five times a day
	One to two times a day	
		26
		26

	i) Around the time your child was conceived	<ul><li>ii) During the first thre months of pregnancy</li></ul>
a) Multivitamins	☐ Yes ☐ No ☐ Don't know	☐ Yes ☐ No ☐ Don't know
b) Vitamin A	☐ Yes ☐ No ☐ Don't know	☐ Yes ☐ No ☐ Don't know
c) Vitamin B	☐ Yes ☐ No ☐ Don't know	☐ Yes ☐ No ☐ Don't know
d) Vitamin C	☐ Yes ☐ No ☐ Don't know	☐ Yes ☐ No ☐ Don't know
e) Vitamin D	☐ Yes ☐ No ☐ Don't know	☐ Yes ☐ No ☐ Don't know
f) Vitamin E	☐ Yes ☐ No ☐ Don't know	☐ Yes ☐ No ☐ Don't know
g) Calcium	☐ Yes ☐ No ☐ Don't know	☐ Yes ☐ No ☐ Don't know
h) Folic Acid	☐ Yes ☐ No ☐ Don't know	☐ Yes ☐ No ☐ Don't know
i) Iron	☐ Yes ☐ No ☐ Don't know	☐ Yes ☐ No ☐ Don't know
j) Zinc	☐ Yes ☐ No ☐ Don't know	☐ Yes ☐ No ☐ Don't know
<ul> <li>Any other nutritional supplement?</li> </ul>	☐ Yes ☐ No ☐ Don't know	Yes No Don't know

#### E23. Please tell us which supplements you have taken/currently take?

E24. a) Did/do you take any herbal remedies?

	i) Around the time your child was conceived Yes No Don't know	ii)	During the of pregna Yes No Don't kr	
	b) If yes, please specify:			
E25.	Did you drink alcohol arour the time your child was co		🗌 Yes	🗌 No
E26.	Do you drink alcohol now?		🗌 Yes	🗌 No

If you answered yes to E25 or E26 go to question E27, if no go to question E30.

#### Please use the image below to help you answer questions E27





E27. On average, how many units of alcohol did/do you drink per week?

i) Around the time your child was conceived	ii) Now			
□ None	□ None			
One to two units	One to two units			
Three to five units	Three to five units			
Five to ten units	Five to ten units			
Ten to twenty units	Ten to twenty units			
Twenty to thirty units	Twenty to thirty units			
More than thirty units	More than thirty units			

E28. On average, how often did/do you drink alcohol?

i) Around the time your child was conceived	ii) Now
□ Less than once per month	Less than once per month
One to three times per month	One to three times per month
One to two times per week	One to two times per week
☐ Three to four times per week	☐ Three to four times per week
Every day or most days	Every day or most days

- E29. 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)

E30.	a) Have you ever smoked cigarette	es regularly? 📋 Yes
	If no, go to question E36	🗌 No
	b) If yes, when did you first start s	moking? Year
E31.		es (Go to question E32) o (Go to question E33)
E32.	On average, how many cigarettes d	o you currently smoke <u>per day?</u>
	Less than one per day	One pack (15-24 per day)
	🗌 One per day	☐ One ½ packs (25-34 per day)
	Two to four per day	Two packs (35-44 per day)
	$\Box$ ½ a pack (five to 14 per day)	More than two packs per day
E33.	<ul> <li>a) If you used to smoke but have s stopped, please tell us when you</li> </ul>	
	<ul> <li>b) If you used to smoke, on average smoke per day?</li> </ul>	ge, how many cigarettes did you used to
	Less than one per day	One pack (15-24 per day)
	🗌 One per day	One ½ packs (25-34 per day)
	Two to four per day	Two packs (35-44 per day)
	☐ ½ a pack (five to 14 per day)	More than two packs per day
E34.	a) Did you smoke at the time your	child was conceived? 🗌 Yes 🗌 No

If you answered no to question E34 a), go straight to question E35



	b)	If yes, on average, how many ciga at the time your child was conceiv	igarettes did you used to smoke <b>per day</b> ceived?			
		Less than one per day	One pack (15-24 per day)			
		One per day	☐ One ½ packs (25-34 per day)			
		Two to four per day	🔲 Two packs (35-44 per day)			
		$\square$ <sup>1</sup> / <sub>2</sub> a pack (five to 14 per day)	More than two packs per day			
E35.	W	here did/do you usually smoke?				
		] Only outside 🛛 Only inside	Both inside and outside			
E36.		ere/are you ever exposed to passiv sure time)?	e smoke e.g. at home, work or during			
		Around the time your child was conceived	ii) Now			
	[	☐ Yes	Yes			
	[	□ No	🗆 No			
	I	f no, go to question E38	If no, go to question E38			
E37.	Но	ow many hours a day were/are you	exposed to passive smoke?			
	-	Around the time your child was conceived	ii) Now			
		□ Less than one hour per day	Less than one hour per day			
		□ One to two hours per day	One to two hours per day			
		☐ Three to four hours per day	□ Three to four hours per day			
	I	☐ More than four hours per day	More than four hours per day			

E38. Did you/do you use any other types of nicotine? (Cross <u>all</u> that apply)

a) Around the time your child was conceived	b) Now
🗆 i) Nicotine gum	$\square$ i) Nicotine gum
🔲 ii) Adhesive patch	$\square$ ii) Adhesive patch
🗆 iii) Nicotine sprays	iii) Nicotine sprays
iv) Nicotine inhalers	$\Box$ iv) Nicotine inhalers
v) Lozenges or tablets	v) Lozenges or tablets
🗆 vi) 'Sinus' or nasal snuff	$\Box$ vi) 'Sinus' or nasal snuff
vii) Chewing tobacco	🛛 vii) Chewing tobacco
🗆 viii) None	🗆 viii) None
□ ix) Other	🗆 xi) Other

#### E39. a) Have you previously used any of the following substances? (Cross all that apply)

	Never	Once a year	Twice a year	Once every	Once a month	Twice a month	Once a week or
				two			more
	_	_	_	months			
i) Cannabis							
ii) Cocaine							
iii) Ecstasy							
iv) Amphetamine							
v) Heroin							
vi) Other (specify below)							

 b) Did you use any of the following substances <u>around the time your child was conceived</u>? (Cross <u>all</u> that apply)

	Never	Once a vear	Twice a year	Once every	Once a month	Twice a month	Once a week or
				two			more
				months			
i) Cannabis							
ii) Cocaine							
iii) Ecstasy							
iv) Amphetamine							
v) Heroin							
vi) Other (specify below)							
L							



c) Do you use any of the following substances **now**? (Cross all that apply)

c) bo you use any of the following	gsubs	lances	<u>110w</u> :	CIUSS		appiy)	
	Never	Once a year	Twice a year	Once every two months	Once a month	Twice a month	Once a week or more
i) Cannabis							
ii) Cocaine							
iii) Ecstasy							
iv) Amphetamine							
v) Heroin							
vi) Other (specify below)							
<ul> <li>i) Vigorous exercise (breathing hard, heart beats rapidly).</li> <li>For example: running, aerobics, martial arts, fast swimming, or a team sport such as football or hockey minutes per week</li> <li>ii) Moderate exercise (heart rate increases slightly, but is not exhausting). For example: fast walking or gentle cycling minutes per week</li> </ul>							
iii) Muscle strengthening act For example: lifting weights yoga			_	ıps, hea mes per		ening or	
E41. On average, how much time	do yo	u sper	d outo	loors?			
i) Around the time your chi conceived	ild wa	5 ii)	Now				
Less than one hour per of	day		Less	than on	e hour p	oer day	
One to two hours per data	ау		One	to two l	nours pe	r day	
Three to four hours per	day		Three	e to fou	r hours (	per day	
Five or more hours per of	day	Г	Five	or more	hours p	er day	_

33

Five or more hours per day

I 

SE	ECTION F - YOUR WELLBEING
F1.	How many close friends do you have (other than your partner)?
F2.	Overall, how would you rate your relationships with your close friends?
F3.	In the year leading up to the birth of this child, did you experience a period of acute stress or an emotional event which had an influence on your state of mind? (Please cross <u>all</u> boxes that apply to you)
	☐ i) Death of a partner
	🗌 ii) Divorce
	iii) Marital separation
	iv) Prison sentence
	v) Death of a parent or close family member
	□ vi) Personal injury or illness
	🗌 vii) Marriage
	viii) Being sacked or laid off from work
	ix) Marital reconciliation
	x) Retirement
	xi) Change in health of family member
	🗌 xii) Pregnancy
	xiii) Sex difficulties
	🗌 xiv) Gaining a new family member
	🗌 xv) Business readjustment
	🗌 xvi) Change in financial state
	xvii) Death of a close friend
_	xviii) Change to a different line of work
	34

F3 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

F4. These questions ask you about your view of the world. Please cross the box for each statement that applies to you.

		Strongly disagree	Disagree	Neutral	Agree	Strongly agree
a)	In uncertain times, I usually expect the best					
b)	It's easy for me to relax					
c)	If something can go wrong for me, it will					
d)	I'm always optimistic about my future					
e)	I enjoy my friends a lot					
f)	It's important for me to keep busy					
g)	I hardly ever expect things to go my way					
h)	I don't get upset too easily					
i)	I rarely count on good things happening to me					
j)	Overall, I expect more good things to happen to me than bad					



F5. 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 <u>one month, as a result of your child's health</u>, how much of a problem **have you** had with...

		Never	Almost never	Some- times	Often	Almost always
a)	I feel tired during the day					
b)	I feel tired when I wake up in the morning					
c)	I feel too tired to do the things I like to do					
d)	I get headaches					
e)	I feel physically weak					
f)	I feel sick to my stomach					
g)	I feel anxious					
h)	I feel sad					
i)	I feel angry					
j)	I feel frustrated					
k)	I feel helpless or hopeless					
I)	I feel isolated from others					
m)	I have trouble getting support from others					
n)	It is hard to find time for social activities					
	I do not have enough energy for social activities					

F5 continued...

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



F6. 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 Some- Often Almost never times Always a) Family activities taking more time П П and effort b) Difficulty finding time to finish Π П  $\square$ household tasks c) Feeling too tired to finish household tasks d) Lack of communication between П family members e) Conflicts between family members п П П f) Difficulty making decisions Π П  $\square$  $\square$ together as a family g) Difficulty solving family problems П П together h) Stress or tension between family Π Π  $\square$ members F7. 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.

	<b>How happy are you with</b> (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?						
	How much information was provided to you about the treatment and course of your child's health condition?						
·	How much information was provided to you about the side effects of your child's treatment?						
, c)	How much information was provided to you about the treatment and course of your child's health condition? How much information was provided to you about the side						

F7 continued...

	How happy are you with	Never	Some- times	Often	Almost always	Always	N/A
d)	How soon information was given to you about your child's test results?						
e)	How often you are updated about your child's health?						
f)	The sensitivity shown to you and your family during your child's treatment?						
g)	The willingness to answer questions that you and your family may have?						
h)	The effort to include your family in discussion of your child's care and other information about your child's health condition?						
i)	How much time the staff give you to ask any questions you may have had about your child's health condition and treatment?						
j)	How well the staff explain your child's health condition and treatment to <b>your child</b> in a way that she/he can understand?						
k)	The time taken to explain your child's health condition and treatment to <b>you</b> in a way that you could understand?						
I)	How well the staff listen to you and your concerns?						
m)	about what to expect during tests and procedures?						
		40					

F7 continued...

Но	w happy are you with:	Never	Some- times	Often	Almost always	Always	N/A
n)	The preparation provided for <b>your</b> <b>child</b> about what to expect during tests and procedures?						
o)	How well the staff respond to your child's needs?						
p)	Efforts to keep your child comfortable and as pain-free as possible?						
q)	How much time the staff take to help you with your child coming back home after hospitalisation?						
r)	The amount of time given to your child to play, talk about her/his feelings, and any questions she/he may have?						
s)	The amount of time spent helping your child with going back to school after hospitalisation?						
t)	The amount of time spent attending to <b>your child's</b> emotional needs?						
u)	The amount of time spent attending to <b>your</b> emotional needs?						
v)	The overall care your child is receiving?						
w)	How friendly and helpful the staff are?						
x)	The way your child is treated at the hospital?						

We are asking these questions to help us understand the challenges families may experience. This will allow us to make recommendations about support that could be made available.

F8. These questions ask you about your feelings and thoughts during the last month.

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



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.

F9. These questions ask you about your feelings and thoughts during the last month.

a) I feel tense or 'wound up'	b) I still enjoy the things I used to enjoy
☐ Most of the time	Definitely as much
🗌 A lot of the time	Not quite so much
From time to time, occasionally	Only a little
🗌 Not at all	☐ Hardly at all
c) I get a sort of frightened feeling as if something awful is about to happen	d) I can laugh and see the funny side of things
Very definitely and quite badly	As much as I always could
🗌 Yes, but not too badly	Not quite so much now
🗌 A little, but it doesn't worry me	Definitely not so much now
🗌 Not at all	🗌 Not at all
e) Worrying thoughts go through	f) l feel cheerful
my mind $\Box$ A great deal of the time	🗌 Not at all
A great deal of the time	🗌 Not often
From time to time, but not too often	─ □ Sometimes

F9 continued...

g) I can sit at ease and feel relaxed	h) I feel as if I am slowed down
Definitely	□ Nearly all the time
Usually	□Very often
🗌 Not often	Sometimes
Not at all	Not at all
<ul> <li>i) I get a sort of frightened feeling like 'butterflies' in the stomach</li> <li>Not at all</li> <li>Occasionally</li> <li>Quite often</li> <li>Very often</li> </ul>	<ul> <li>j) I have lost interest in my appearance</li> <li>Definitely</li> <li>I don't take as much care as I should</li> <li>I may not take quite as much care</li> <li>I take just as much care as ever</li> </ul>
k) I feel restless as I have to be on the move	l) I look forward with enjoyment to things
	-
on the move	enjoyment to things
on the move	enjoyment to things
on the move Very much indeed Quite a lot	<ul> <li>enjoyment to things</li> <li>As much as I ever did</li> <li>Rather less than I used to</li> </ul>
on the move         Very much indeed         Quite a lot         Not very much	<ul> <li>enjoyment to things</li> <li>As much as I ever did</li> <li>Rather less than I used to</li> <li>Definitely less than I used to</li> </ul>
<ul> <li>on the move</li> <li>Very much indeed</li> <li>Quite a lot</li> <li>Not very much</li> <li>Not at all</li> <li>m) I get sudden feelings of</li> </ul>	<ul> <li>enjoyment to things</li> <li>As much as I ever did</li> <li>Rather less than I used to</li> <li>Definitely less than I used to</li> <li>Hardly at all</li> <li>n) I can enjoy a good book or</li> </ul>
on the move Very much indeed Quite a lot Not very much Not at all m) I get sudden feelings of panic	<ul> <li>enjoyment to things</li> <li>As much as I ever did</li> <li>Rather less than I used to</li> <li>Definitely less than I used to</li> <li>Hardly at all</li> <li>n) I can enjoy a good book or radio or TV Programme</li> </ul>
<ul> <li>on the move</li> <li>Very much indeed</li> <li>Quite a lot</li> <li>Not very much</li> <li>Not at all</li> <li>m) I get sudden feelings of panic</li> <li>Very often indeed</li> </ul>	<ul> <li>enjoyment to things</li> <li>As much as I ever did</li> <li>Rather less than I used to</li> <li>Definitely less than I used to</li> <li>Hardly at all</li> <li>n) I can enjoy a good book or radio or TV Programme</li> <li>Often</li> </ul>



F10. 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 <u>six months?</u>

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

F10 continued...

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



F11.	Overall, do you think that your child has difficulties in <b>one or more</b> of the
	following areas: emotions, concentration, behaviour or being able to get on
	with other people?

	🔲 Yes - minor difficulti	ies	Yes - sever	e difficulties	
	🔲 Yes - definite difficu	lties	🗌 No		
F12.	If you have answered "y these difficulties:	<u>es"</u> , please a	answer the foll	owing questic	ons about
	a) How long have these	difficulties b	peen present?		
	Less than a month	] 1-5 mont	hs 🔲 6-12 m	onths 🗌 Ov	ver a year
	<ul> <li>b) Do the difficulties up</li> <li>Not at all Only</li> <li>c) Do the difficulties interareas?</li> </ul>	a little [ erfere with y	Quite a lot Quite child's eve		he following
		Not at all	Only a little	Quite a lot	A great deal
	i) Home life				
	ii) Friendships				
	iii) Classroom learning				
	iv) Leisure activities				
	d) Do the difficulties pur	t a burden o	n you or the fa	mily as a who	le?
	🗌 Not at all 🛛 🗍 Only	a little	Quite a lot	🗌 A great	t deal

F13. a) How noticeable do you think your child's cleft is to other people?

🗌 N	ot at all		Makes no difference		Very noticeabl	e
-----	-----------	--	---------------------	--	----------------	---

- A little Quite 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 <u>six months?</u>

	Never	Almost never	Some- times	Often	Almost always
<ul> <li>i) I feel that the cleft has dominated my experience of bringing up my child</li> </ul>					
ii) I feel that it is my fault that my child was born with a cleft					
<li>iii) I struggle to come to terms with my child's cleft</li>					
iv) I worry that I am unable to care for my child because of the cleft					
v) I worry about other health problems my child may have					
vi) I worry that the cleft is affecting my relationship with my child					
vii) I worry about the impact of my child's cleft on their learning at school					
viii) I worry about the impact of my child's cleft on their self-confidence					
ix) I worry about my child's future treatment	t 🗌				
<ul> <li>x) I feel comfortable talking to my child about their cleft</li> </ul>					
xi) I feel optimistic about my child's future					
xii) I feel that there are many positives to having a child with a cleft					



F13. c) If you feel that there are many positives to having a child with cleft, please specify what these are in the box below:

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

F14.	Yes	Some- times	Not yet
a) Without you giving help by pointing or repeating directions, does your child follow three directions that are unrelated to one another? For example, "Clap your hands, walk to the door, and sit down."			
<ul><li>b) Does your child use four and five word</li><li>sentences? For example, does your child say,</li><li>"I want the car"?</li></ul>			
c) When talking about something that has already happened, does your child use words that end in "-ed", such as "walked", "jumped", or "played"?			
d) Does your child use comparison words, such as "heavier," "stronger," or "shorter"?			
e) When you ask your child a question does he/she respond appropriately? For example, "What do you do when you are tired?", your child may say "go to sleep", "go to bed" or "lie down".			
f) Is your child able to repeat the following sentences back to you, without any mistakes? "Jane hides her shoes for Maria to find" and "Alex read the blue book under his bed"			

F15.	Yes	Some- times	Not yet
a) While standing, can your child throw a ball overhand in the direction of a person standing at least 6 feet away?			
b) Can your child catch a large ball with both hands?			
c) Without holding onto anything, can your child stand on one foot for at least 5 seconds without losing his/her balance and putting his/her foot down?			
d) Can your child walk on his/her tiptoes for 15 feet?			
e) Can your child hop forward on one foot for a distance of 4-6 feet without putting down the other foot?			
f) Can your child skip using alternating feet?			
F16.	Yes	Some- times	Not yet
F16. a) If tracing a straight line on a piece of paper, can your child trace over the line without going off the line more than once?	Yes		
a) If tracing a straight line on a piece of paper, can your child trace over the line without going off the		times	yet
a) If tracing a straight line on a piece of paper, can your child trace over the line without going off the line more than once? b) When drawing a picture of a person, does your		times	yet
<ul> <li>a) If tracing a straight line on a piece of paper, can your child trace over the line without going off the line more than once?</li> <li>b) When drawing a picture of a person, does your child draw a person with a head, body, arms AND legs?</li> <li>c) When using scissors, can your child cut the paper</li> </ul>			yet
<ul> <li>a) If tracing a straight line on a piece of paper, can your child trace over the line without going off the line more than once?</li> <li>b) When drawing a picture of a person, does your child draw a person with a head, body, arms AND legs?</li> <li>c) When using scissors, can your child cut the paper in a more or less straight line?</li> <li>d) Is your child able to copy basic shapes (e.g.</li> </ul>			yet



F17.	Yes	Some- times	Not yet
a) If shown three circles of varying size, is your child able to identify which circle is the smallest?			
b) Can your child identify five different colours (e.g. red, blue, yellow, black, white)?			
c) Can your child count up to 15 without making mistakes? (If your child can count to 12 without making mistakes, mark "sometimes")			
<ul><li>d) Can your child finish a sentence using a word that means the opposite of another word (e.g.</li><li>"Ice is cold, and fire is <i>hot</i>")?</li></ul>			
e) Does your child know the names of numbers if the number is written down (e.g. 1= one, 2 = two, 3 = three)?			
f) Can your child name at least four letters in his/her name if asked "what letter is this?"			

F18.	Yes	Some- times	Not yet
a) Can your child serve himself/herself, taking food from one container to another, using utensils?			
b) Can your child wash his/her hands and dry them with a towel without help?			
c) Can your child tell you at least four of the following? Their first name/age/city they live in/last name/gender/telephone number.			
d) Can your child dress and undress himself/ herself, including the use of buttons and zips?			
e) Can your child use the toilet by himself/herself?			
f) Does your child usually take turns and share with other children?			

F19. a) i. Do you think your child hears well? ii. If no, please explain.

🗌 Yes 🔲 No
b) i. Do you think your child talks like other children his/her age? ii. If no, please explain.
Yes No
c) i. Can you understand most of what your child says? ii. If no, please explain.
Yes No
d) i. Can other people understand most of what your child says? ii. If no, please explain.
e) i. Do you think your child walks, runs, and climbs like other children his/her age? ii. If no, please explain.
🗌 Yes 🔲 No
f) i. Does either parent have a family history of childhood deafness or hearing impairment? ii. If yes, please explain.
🗌 Yes 🔲 No
g) i. Do you have any concerns about your child's vision? ii. If yes, please explain.
Yes No
h) i. Has your child had any medical problems in the last several months? ii. If yes, please explain.
🗌 Yes 🔲 No
i) i. Do you have any concerns about your child's behaviour? ii. If yes, please explain.
Yes No
j) i. Does anything about your child worry you? ii. If yes, please explain.
Yes No



F20. 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	Rarely or never	Cross if this is a concern
a) Does your child look at you when you talk to him/her?			
b) Does your child cling to you more than you expect?			
c) Does your child like to be hugged or cuddled?			
d) Does your child talk and/or play with adults he/she knows well?			
e) When upset can your child calm down within 15 minutes?			
f) Does your child seem too friendly with strangers?			
g) Can your child settle himself/herself down after periods of exciting activity?			
h) Does your child seem happy?			
i) Does your child cry, scream, or have tantrums for long periods of time?			
j) Is your child interested in things around him/her such as people, toys and food?			
k) Does your child go to the bathroom by himself/ herself? (Reminders and help with wiping are okay)			
I) Does your child have eating problems (that are not related to their cleft) such as stuffing foods, vomiting or eating nonfood items?			

F20. continued	Most of the time		Cross if this is a concern
m) Can your child stay with activities he enjoys for at least 15 minutes (not including watching television)?			
n) Do you and your child enjoy mealtimes together?			
o) Does your child do what you ask him/her to do?			
p) Does your child seem more active than other children his/her age?			
q) Does your child sleep at least 8 hours in a 24 hour period?			
r) Does your child use words to tell you what he/she wants or needs?			
s) Does your child use words to describe his/her feelings and the feelings of others, such as, "I'm happy," "I don't like that," or "She's sad"?			
t) Does your child move from one activity to the next with little difficulty, such as from playtime to mealtime?			
u) Does your child explore new places, such as a park or a friend's home?			
<ul> <li>v) Does your child do things over and over and can't seem to stop? Examples include rocking or hand flapping.</li> </ul>			
w) Does your child hurt himself/herself on purpose?			
x) Does your child follow rules (at home, at school)?			



F20 continued	Most of the time		Cross if this is a concern
y) Does your child destroy or damage things on purpose?			
z) Does your child stay away from dangerous things, such as fire and moving cars?			
aa) Does your child show concern for other people's feelings? For example, does he/she look sad when someone is hurt?			
bb) Do other children like to play with your child?			
cc) Does your child like to play with other children?			
dd) Does your child try to hurt other children, adults, or animals (for example, by kicking or biting)?			
ee) Does your child take turns and share when playing with other children?			
ff) Does your child show an interest or knowledge of adult sexual language and activity?			
gg) Has anyone expressed concerns about your child's behaviours? If you cross "sometimes" or "most of the time" please specify in the box below.			

## SECTION G - FURTHER INFORMATION

G1. How old were you when you had your first menstrual period?

G2.	Have you regularly experienced any of the following problems with your
	menstrual period? (Cross <u>all</u> that apply)

- □ a) Feeling depressed or irritable □ d) Menstrual pains
- b) Irregular periods

u)	wenstruar pains
e)	Heavy bleeding

vears

□ c) Periods lasting longer than one week □ f) Anaemia

G3. Which of these types of contraceptives have you used in the past? (Cross <u>all</u> that apply)

🗌 a)	Condom	🗌 g)	Mini pill
🗌 b)	Diaphragm	🗌 h)	Spermicide
🗌 c)	Intrauterine Device (IUD) / coil	🗌 i)	Withdrawal
🗌 d)	Hormone Intrauterine Device (IUD) / coil	□ j)	None
🗌 e)	Hormone injection	🗌 k)	Other
f)	Pill	If othe	er, please specify:

G4. If you have ever used the Hormone Intrauterine Device/Hormone injection/pill/mini pill, how long altogether have you used them?

Less than one year	4-6 years	10 years or more
1-3 years	7-9 years	Not applicable

G5. If applicable, how old were you when you first used hormonal contraception?

In the following questions, we ask you about your pregnancies. When we ask about 'this pregnancy', please answer in relation to your child who was born with a cleft.

Please remember that we are asking a broad range of questions. If you experienced any problems during this pregnancy it does not necessarily mean that this is what caused your child's cleft.

G6. How many times have you been pregnant in your life?





G7. How many of these pregnancies ended in (Answ	ver <u>all</u> that apply)				
i) Live birth - full term ii) Still birth	iii) Premature birth				
iv) Miscarriage v) Ectopic pregn	ancy vi) Termination				
vii) This is my first/only pregnancy (Cross b	ox if this answer applies to you)				
G8. If applicable, how were your child(ren) delivered?					
<ul> <li>a) This pregnancy (Cross <u>one</u> box only)</li> <li>i) Vaginal delivery</li> <li>ii) Emergency caesarean/c-section</li> <li>iii) Planned caesarean/c-section</li> <li>iv) Other assisted methods</li> <li>b) Past pregnancies (Cross <u>all</u> that apply)</li> <li>i) Vaginal delivery</li> <li>ii) Emergency caesarean/c-section</li> <li>iii) Planned caesarean/c-section</li> </ul>					
<ul> <li>G9. a) Was this pregnancy planned? ☐ Yes ☐ No</li> <li>b) If yes, approximately how long did it take you to get pregnant?</li></ul>					
G10. Did you have an amniocentesis (amnio) performed for this pregnancy?					
G11. Did you experience any of these problems durin	g this pregnancy?				
i) During the first three ii) Rest of the pregnancy months of pregnancy					
a) Inflammation of the Yes Medication used (if known) b) A heavy cold Yes No Medication used (if known)					
c) Influenza/Flu					

G11. Continued		i) During the first three months of pregnancy	ii) Rest of the pregnancy
d) An infection	Yes No	Medication used (if known)	Medication used (if known)
e) A fever with a temperature above	☐Yes ☐No	Medication used (if known)	Medication used (if known)
<u>38 degrees Celsius</u> f) Extreme nausea	Yes	Medication used (if known)	Medication used (if known)
g) Extreme nausea with vomiting	Yes No	Medication used (if known)	Medication used (if known)
h) High blood pressure	Yes No	Medication used (if known)	Medication used (if known)
i) Low blood pressure	☐Yes ☐No	Medication used (if known)	Medication used (if known)
j) Gestational diabetes	☐Yes ☐No	Medication used (if known)	Medication used (if known)
k) Thyroid problems	Yes No	Medication used (if known)	Medication used (if known)
l) Pelvic problems	Yes No	Medication used (if known)	Medication used (if known) Ves No
m) Anaemia	Yes No	Medication used (if known)	Medication used (if known)
n) Vaginal bleeding	Yes No	Medication used (if known)	Medication used (if known)
o) Sleeping problems	Yes No	Medication used (if known)	Medication used (if known)
p) Rubella	☐Yes ☐No	Medication used (if known)	Medication used (if known)



G11. Continued	i) During the first three months of pregnancy	ii) Rest of the pregnancy
q) Jaundice	Medication used (if known)	Medication used (if known)
r) Syphilis	Medication used (if known)	Medication used (if known)
s) Pre-eclampsia	Medication used (if known)	Medication used (if known)
t) Toxoplasmosis	Medication used (if known)	Medication used (if known)

G12. Did you take any other medication during this pregnancy (including over the counter medication)?

	i) During the first three months of pregnancy		ii) Rest of the pregnancy
	If yes, please specify:		If yes, please specify:
Yes		Yes	
No		No	

G13. Were you admitted to hospital unexpectedly during the pregnancy due to an illness or other complication?

	a) During the first three months of pregnancy		b) Rest of the pregnancy
i)	🗌 Yes 🔲 No	i)	Yes 🗌 No 🗌
ii)	If yes, length of stay (days)	ii)	If yes, length of stay (days)
c) W	hat was the cause of your hospi	tal adn	nission?
L			

G14. Did you receive any treatment involving anaesthetics during this pregnancy?

	i) During the first three months of pregnancy	ii) Rest of the pregnancy
	🗌 Yes 🗌 No 🗌 Don't know	🗌 Yes 🗌 No 🗌 Don't know
G15.	Did you have an x-ray during this pre	gnancy?
	i) During the first three months of pregnancy	ii) Rest of the pregnancy
	🗌 Yes 🗌 No 🗌 Don't know	🗌 Yes 🗌 No 🗌 Don't know
		earlier in this questionnaire, the following ant with your child who was born with a cleft
G16.	a) Did you smoke during this pregna	ancy? 🗌 Yes 🗌 No
	b) If yes, when? (Cross <u>all</u> that apply	y) 🔲 i) 0 - 3 months 🔲 ii) 4 - 9 months
	c) If yes, how many did you smoke p	er day?
	Less than one per day	🗌 One pack (15-24 per day)
	🔲 One per day	One ½ packs (25-34 per day)
	Two to four per day	🔲 Two packs (35-44 per day)
	½ a pack (five to 14 per day)	More than two packs per day
G17.	a) Did you drink alcohol during this	pregnancy? 🗌 Yes 🗌 No
	b) If yes, when? (Cross <u>all</u> that apply	y) 🗌 i) 0 - 3 months 🔲 ii) 4 - 9 months
	c) If yes, how much alcohol did you o to help answer the question)	drink <u>per week?</u> (See image on page 28
	□ None	Ten to twenty units
	One to two units	Twenty to thirty units
	Three to five units	More than thirty units
	Five to ten units	
	6	0

G18.	a)	Did you drink caffeinated drinks (such as tea, coffee and fizzy drinks) during this pregnancy?  Yes No		
	b)	If yes, when? (Cross <u>all</u> that apply)	<ul> <li>□ i) 0 - 3 months</li> <li>□ ii) 4 - 9 months</li> </ul>	
	c)	If yes, how often did you drink caffeir	nated drinks?	
		<ul> <li>Less than once a month</li> <li>One or two cups a week</li> <li>One or two cups a day</li> </ul>	<ul><li>Three to five cups a day</li><li>More than five cups a day</li></ul>	
G19.	a)	Did you use drugs during this pregna	ncy? 🗌 Yes 🗌 No	
	b)	If yes, when? (Cross <u>all</u> that apply)	<ul> <li>i) 0 - 3 months</li> <li>ii) 4 - 9 months</li> </ul>	
	c)	If yes, how often did you use them? (	Cross <u>all</u> that apply)	

	Never	Once a year	Twice a year	Once every two months	Once a month	Twice a month	Once a week or more
i) Cannabis							
ii) Cocaine							
iii) Ecstasy							
iv) Amphetamine							
v) Heroin							
vi) Other (specify below)							

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

- G20. What is the highest educational qualification <u>your partner</u> has obtained? (Cross <u>one</u> box only)
  - □ One or more O Levels/CSEs/GCEs (any grades)
  - □ Five or more O Levels/CSEs (grade 1)/GCSEs (grades A\*-C)/School Certificate
  - □ One or more A Levels/AS Levels
  - Two or more A Levels/Four or more AS Levels/Higher School Certificate
  - □ NVQ Level 1/Foundation GNVQ
  - □ NVQ Level 2/Intermediate GNVQ
  - □ NVQ Level 3/Advanced GNVQ
  - □ NVQ Levels 4-5/HNC/HND
  - □ First degree (e.g. BA/BSc)
  - □ Higher degree (e.g. MA, PhD, postgraduate PGCE)
  - □ Other qualifications (e.g. City and Guilds, RSA/OCR, BTEC/Edexcel)
  - Overseas qualifications (please specify)
  - No qualifications
  - Don't know
  - □ Other (please specify)

## G21. What is your partner's current employment status? (Cross one box only)

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



G22. This table shows income in weekly, monthly and annual amounts. Which of the amounts on this list represents YOUR PARTNER'S individual total income from all jobs, tax credits, benefits and other sources after tax when added together? (Cross <u>one</u> box only)

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

Please go to section Z on the back page.

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## SECTION Z

Z1.	This questionnaire was completed by:
	a) Child's biological mother
	b) Child's step mother
	c) Child's adoptive / foster mother
	d) 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 DD MM YYYY you complete this / / / / / / / / / / / / / / / / / / /
Z4.	Please give <b>your</b> DD MM YYYY date of birth
Z5.	Please give your DD MM YYYY child's date of / / / / / / / / / / / / / / / / / /

## 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

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