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

ID LABEL

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You and Your Child

Mother's questionnaire
Postnatal recruitment

This questionnaire is for the child's mother.

University of BRISTOL

UWE BRISTOL University of the West of England

THE SCAR FREE FOUNDATION

VTCT WORLD CLASS QUALIFICATIONS

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(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.

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 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:

☒

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 Caribbean	☐	☐	☐
White and Black African	☐	☐	☐
White and Asian	☐	☐	☐
Any other mixed background (please cross box and specify)	☐	☐	☐

c) Asian or Asian British	**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 British	**i) You**	**ii) Your mother**	**iii) Your father**
Caribbean	☐	☐	☐
African	☐	☐	☐
Any other Black background (please cross box and specify)	☐	☐	☐

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 of birth:

A3. How long have you lived in the UK? a) Since Birth ☐ b) If not since birth, number of years:

A4. What is your religion?

- ☐ None
- ☐ Christian (Including Church of England, Catholic, Protestant and all other Christian denominations)
- ☐ Buddhist
- ☐ Hindu
- ☐ Jewish
- ☐ Sikh
- ☐ Any other religion (please specify)

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

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

☐☐ Your mother ☐☐ 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 **(when looking at your child)**?

☐ Right ☐ Left ☐ Don't know ☐ Not applicable

SECTION B - WORK AND EDUCATION

B1. What is the highest educational qualification you have 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 specifiy) [ ]

B2. Overall, how would you rate your school experience?

☐ Poor ☐ Fair ☐ Good ☐ Excellent

B3. Overall, how would you rate your school academic performance?

☐ Poor ☐ Fair ☐ Good ☐ Excellent

B4. Overall, how would you rate your school enjoyment?

☐ Poor ☐ Fair ☐ Good ☐ Excellent

B5. Overall, how would you rate your relationships with your school teachers?

☐ Poor ☐ Fair ☐ Good ☐ Excellent

B6. Overall, how would you rate your relationships with your school friends?

☐ Poor ☐ Fair ☐ Good ☐ Excellent

B7. a) Have you ever experienced teasing and bullying? ☐ Yes ☐ No

b) If yes, how bad do you feel this teasing and bullying was?
☐ Not very bad ☐ Moderate ☐ Very bad

B8. What is your current employment status? **(Cross <u>one</u> box only)**

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

B9. What is your current/most recent occupation? **(Cross <u>one</u> box only).**
See below and on the next page for examples of occupation types.

- ☐ Professional/executive
- ☐ Small business, proprietor, sales
- ☐ Clerical/administrative
- ☐ Skilled worker
- ☐ Semi-skilled worker
- ☐ Unskilled worker
- ☐ Student/school pupil
- ☐ Homemaker
- ☐ Volunteer worker
- ☐ Other (please specify below)

EXAMPLES OF OCCUPATION TYPES

<u>Professional/Executive:</u> 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.

Semi-skilled worker: 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?

☐☐ years ☐☐ 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

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

Medical leave ☐

Leave of absence ☐

Child was ill ☐

Other (please specify below) ☐

☐

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

B14. What are your current working hours? **(Cross <u>one</u> 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?

	Disagree	Disagree Mostly	Agree Mostly	Agree
a) I do physically heavy work	☐	☐	☐	☐
b) My work is very stressful	☐	☐	☐	☐
c) I learn a lot at work	☐	☐	☐	☐
d) My work is very monotonous	☐	☐	☐	☐
e) My work demands a lot of me	☐	☐	☐	☐
f) I am able to decide how my work is carried out	☐	☐	☐	☐
g) There is a good team spirit at my place of work	☐	☐	☐	☐
h) I enjoy my work	☐	☐	☐	☐

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
- ☐ l) 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

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

- ☐ Buying it with the help of a mortgage or loan
- ☐ 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...

b) Number of children/stepchildren who live with you ☐☐

c) Number of siblings who live with you ☐☐

d) Number of parents who live with you ☐☐

e) Number of other relatives who live with you ☐☐

f) Number of unrelated individuals who live with you ☐☐

C5. How long have you lived in this current household arrangement?

☐☐ years AND/OR ☐☐ months AND/OR ☐☐ weeks

C6. What is your current marital status?

☐ Single ☐ Domestic partner ☐ Married

☐ Separated ☐ Divorced ☐ Widowed

☐ Civil Union

C7. How long have you lived in this current arrangement?

☐☐ years AND/OR ☐☐ months AND/OR ☐☐ weeks

C8. What is your marital history?

a) Number of marriages or civil unions ☐☐

b) Number of times separated ☐☐

c) Number of times divorced ☐☐

d) Number of times widowed ☐☐

C9. 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	☐	☐	☐	☐	☐
b) My partner and I have problems in our relationship	☐	☐	☐	☐	☐
c) I am very happy in my relationship	☐	☐	☐	☐	☐
d) My partner is usually understanding	☐	☐	☐	☐	☐
e) I often think about ending our relationship	☐	☐	☐	☐	☐
f) I am satisfied with my relationship with my partner	☐	☐	☐	☐	☐
g) We often disagree about important decisions	☐	☐	☐	☐	☐
h) I have been lucky in my choice of a partner	☐	☐	☐	☐	☐
i) We agree about how children should be raised	☐	☐	☐	☐	☐
j) I think my partner is satisfied with our relationship	☐	☐	☐	☐	☐

C10. a) Is this your first biological child? Yes ☐ No ☐

b) Please tell us all of your biological children's date of birth and gender?

	Date of Birth (dd/mm/yyyy)	Gender
i) First child (first born)	☐☐/☐☐/☐☐☐☐	☐ Male ☐ Female
ii) Second child	☐☐/☐☐/☐☐☐☐	☐ Male ☐ Female
iii) Third child	☐☐/☐☐/☐☐☐☐	☐ Male ☐ Female
iv) Fourth child	☐☐/☐☐/☐☐☐☐	☐ Male ☐ Female
v) Fifth child	☐☐/☐☐/☐☐☐☐	☐ Male ☐ Female

C11. a) Are any of your biological children from a previous relationship(s)? ☐ Yes ☐ No

b) If yes, please indicate which children (Cross **all** that apply):

☐ i) First ☐ ii) Second ☐ iii) Third ☐ iv) Fourth ☐ v) Fifth

C12. a) Do you have any stepchildren? ☐ Yes ☐ No

b) If yes, please tell us your stepchildren's date of birth and gender:

	Date of Birth (dd/mm/yyyy)	**Gender**
i) First stepchild (eldest)	☐☐/☐☐/☐☐☐☐	☐ Male ☐ Female
ii) Second stepchild	☐☐/☐☐/☐☐☐☐	☐ Male ☐ Female
iii) Third stepchild	☐☐/☐☐/☐☐☐☐	☐ Male ☐ Female
iv) Fourth stepchild	☐☐/☐☐/☐☐☐☐	☐ Male ☐ Female
v) Fifth stepchild	☐☐/☐☐/☐☐☐☐	☐ Male ☐ Female

C13. What is your first language? ☐ English ☐ Other (please specify below)

C14. If you speak a language other than English, do you often speak this language in your home? ☐ Yes ☐ No

SECTION D - HEALTH AND ILLNESS

D1. Please tell us if **YOU** were born:
- ☐ At full term
- ☐ Prematurely
- ☐ Don't know

D2. What was **YOUR** birth weight (if known)?

Lbs ☐☐ Oz ☐☐ OR Kg ☐☐.☐☐ ☐ Don't know

D3. a) Are **YOU** a twin or multiple? ☐ Yes ☐ No

b) If yes, are **YOU**:
- ☐ An identical twin (monozygotic)
- ☐ A non-identical twin (dizygotic)
- ☐ Multiple
- ☐ Don't know

D4. a) When **YOU** were a child, did **YOU** 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?

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

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

Mental 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 **YOU** been diagnosed with a cleft lip or palate?

☐ No ☐ Cleft palate ☐ Submucous cleft palate
☐ Cleft lip ☐ Cleft lip and palate ☐ Don't know

b) If yes, is your cleft unilateral (on one side of your mouth) or bilateral (on both sides of your mouth)?

☐ Unilateral ☐ Bilateral ☐ Don't know

D10. Has any relative in **your family including your other children <u>and</u> your child's biological father and his family**, been diagnosed with a cleft lip or palate? (If this includes your other children, please also give their date of birth)

a) i) Please tell us who in your family? ii) What was their cleft type? iii) Was their cleft:

	☐ Cleft lip	☐ Unilateral
	☐ Cleft palate	☐ Bilateral
	☐ Cleft lip and palate	☐ Not known
	☐ Submucous cleft palate	
	☐ Not known	

b) i) Please tell us who in your family? ii) What was their cleft type? iii) Was their cleft:

	☐ Cleft lip	☐ Unilateral
	☐ Cleft palate	☐ Bilateral
	☐ Cleft lip and palate	☐ Not known
	☐ Submucous cleft palate	
	☐ Not known	

c) i) Please tell us who in your family? ii) What was their cleft type? iii) Was their cleft:

	☐ Cleft lip	☐ Unilateral
	☐ Cleft palate	☐ Bilateral
	☐ Cleft lip and palate	☐ Not known
	☐ Submucous cleft palate	
	☐ Not known	

d) i) Please tell us who in your family? ii) What was their cleft type? iii) Was their cleft:

	☐ Cleft lip	☐ Unilateral
	☐ Cleft palate	☐ Bilateral
	☐ Cleft lip and palate	☐ Not known
	☐ Submucous cleft palate	
	☐ Not known	

D10. Continued...

e) i) Please tell us who in your family?

ii) What was their cleft type?

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

iii) Was their cleft:

- ☐ Unilateral
- ☐ Bilateral
- ☐ Not known

f) i) Please tell us who in your family?

ii) What was their cleft type?

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

iii) Was their cleft:

- ☐ Unilateral
- ☐ Bilateral
- ☐ Not known

D11. a) During the pregnancy with your child, did you have any infectious diseases? ☐ Yes ☐ No

b) If yes, please specify below:

D12. Have you ever been diagnosed with fertility problems? ☐ Yes ☐ No

D13. a) Was your child conceived using assisted methods? ☐ Yes ☐ No

b) If yes, please tell us more:

SECTION E - YOUR LIFESTYLE

E1. What is your height? feet ☐ inches ☐☐ OR m ☐ . cm ☐☐

E2. What is your current weight? stone ☐☐ lbs ☐☐ OR kg ☐☐☐ . ☐☐

E3. What is the heaviest you have weighed since you were 16 years old (Excluding pregnancy)? stone ☐☐ lbs ☐☐ OR kg ☐☐☐ . ☐☐

E4. What is the lightest you have weighed since you were 16 years old? stone ☐☐ lbs ☐☐ OR kg ☐☐☐ . ☐☐

E5. Have you ever dieted or limited your food intake? ☐ Yes ☐ No

E6. If yes, how old were you the first time you dieted or limited your food intake? ☐☐ years

E7. Have you ever used any of the following methods to control your weight? **(Cross <u>all</u> that apply)**

☐ i) Vomiting ☐ iv) Hard physical exercise
☐ ii) Laxatives ☐ v) Medication
☐ iii) Fasting ☐ vi) None

E8. How would you describe your general diet? **(Cross <u>one</u> box only)**

☐ I have a varied diet ☐ I eat a vegan diet
☐ I eat a vegetarian diet ☐ Other (please specify below)

☐

E9. On average, how often do you eat fruit and vegetables (including fruit juice)?

☐ Never or rarely
☐ Twice a month
☐ One to three times a week
☐ Four to seven times a week
☐ More than once a day

E10. On average, how often do you eat milk and dairy products (such as cheese and yoghurt)?

- ☐ Never or rarely
- ☐ Twice a month
- ☐ One to three times a week
- ☐ Four to seven times a week
- ☐ More than once a day

E11. On average, how often do you eat protein-rich products (such as meat, fish, eggs and beans)?

- ☐ Never or rarely
- ☐ Twice a month
- ☐ One to three times a week
- ☐ Four to seven times a week
- ☐ More than once a day

E12. On average, how often do you eat products containing fat and sugar (such as chocolate, biscuits, cakes and ice cream)?

- ☐ Never or rarely
- ☐ Twice a month
- ☐ One to three times a week
- ☐ Four to seven times a week
- ☐ More than once a day

E13. On average, how often do you eat starchy products (such as bread, rice, potatoes and pasta)?

- ☐ Never or rarely
- ☐ Twice a month
- ☐ One to three times a week
- ☐ Four to seven times a week
- ☐ More than once a day

E14. On average, how often do you eat wholegrain food varieties (such as wholegrain cereal and bread)?

- ☐ Never or rarely
- ☐ Twice a month
- ☐ One to three times a week
- ☐ Four to seven times a week
- ☐ More than once a day

E15. On average, how often do you eat meals and sandwiches bought from canteens/petrol stations/corner shops?

- ☐ Never or rarely
- ☐ Twice a month
- ☐ One to three times a week
- ☐ Four to seven times a week
- ☐ More than once a day

E16. On average, how often do you eat foods or meals from a takeaway outlet or fast-food restaurant?

- ☐ Never or rarely
- ☐ Twice a month
- ☐ One to three times a week
- ☐ Four to seven times a week
- ☐ More than once a day

E17. On average, how often do you eat 'ready meals' (such as microwavable or oven-ready meals)?

- ☐ Never or rarely
- ☐ Twice a month
- ☐ One to three times a week
- ☐ Four to seven times a week
- ☐ More than once a day

E18. On average, how often do you drink caffeinated tea or coffee?

- ☐ Never or rarely
- ☐ One or two cups a week
- ☐ One or two cups a day
- ☐ Three to five cups a day
- ☐ More than five cups a day

E19. On average, how often do you drink herbal tea or decaffeinated tea or coffee?

- ☐ Never or rarely
- ☐ One or two cups a week
- ☐ One or two cups a day
- ☐ Three to five cups a day
- ☐ More than five cups a day

E20 On average, how often do you drink fizzy drinks (such as coke or lemonade)?

- ☐ Never or rarely
- ☐ One or two times a week
- ☐ One to two times a day
- ☐ Three to five times a day
- ☐ More than five times a day

E21. On average, how often do you drink energy drinks?

- ☐ Never or rarely
- ☐ One to two times a week
- ☐ One to two times a day
- ☐ Three to five times a day
- ☐ More than five times a day

E22. On average, how often do you drink water?

- ☐ Never or rarely
- ☐ One to two times a week
- ☐ One to two times a day
- ☐ Three to five times a day
- ☐ More than five times a day

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

	i) Around the time your child was conceived	ii) During the first three months of pregnancy
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
k) Any other nutritional supplement?	☐ Yes ☐ No ☐ Don't know	☐ Yes ☐ No ☐ Don't know

l) If yes to k), please specify: ☐

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 first three months of pregnancy

☐ Yes
☐ No
☐ Don't know

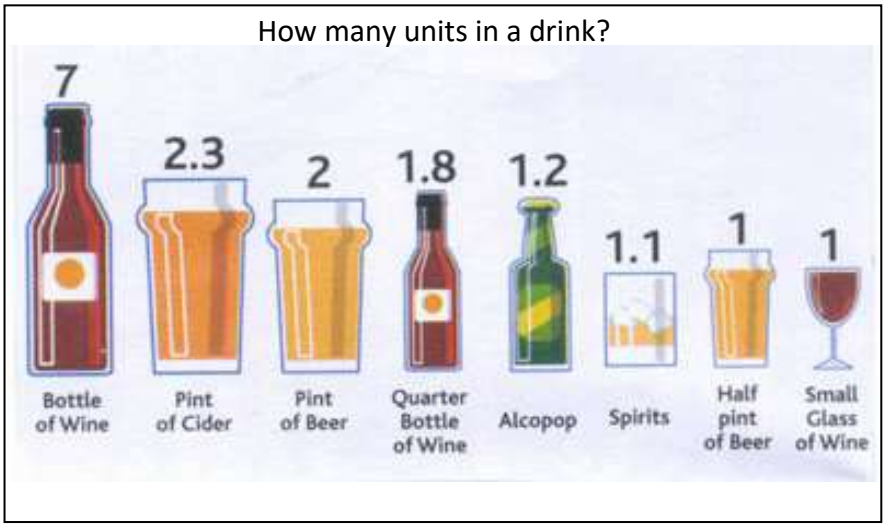
b) If yes, please specify:

E25. Did you drink alcohol around the time your child was conceived? ☐ 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 question 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 cigarettes regularly? ☐ Yes

If no, go to question E36 ☐ No

b) If yes, when did you first start smoking? Year ☐☐☐☐

E31. Do you currently smoke? ☐ Yes **(Go to question E32)**

☐ No **(Go to question E33)**

E32. 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

E33. a) If you used to smoke but have since stopped, please tell us when you quit? Year ☐☐☐☐

b) If you used to smoke, on average, how many cigarettes did you used to 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

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 cigarettes did you used to smoke **per day** at the time your child was conceived?

- ☐ 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

E35. Where did/do you usually smoke?

☐ Only outside ☐ Only inside ☐ Both inside and outside

E36. Were/are you ever exposed to passive smoke e.g. at home, work or during leisure time)?

i) Around the time your child was conceived

☐ Yes

☐ No

If no, go to question E38

ii) Now

☐ Yes

☐ No

If no, go to question E38

E37. How many hours a day were/are you exposed to passive smoke?

i) Around the time your child was conceived

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

ii) Now

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

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

a) Around the time your child was conceived

- ☐ i) Nicotine gum
- ☐ ii) Adhesive patch
- ☐ iii) Nicotine sprays
- ☐ iv) Nicotine inhalers
- ☐ v) Lozenges or tablets
- ☐ vi) 'Snus' or nasal snuff
- ☐ vii) Chewing tobacco
- ☐ viii) None
- ☐ ix) Other

b) Now

- ☐ i) Nicotine gum
- ☐ ii) Adhesive patch
- ☐ iii) Nicotine sprays
- ☐ iv) Nicotine inhalers
- ☐ v) Lozenges or tablets
- ☐ vi) 'Snus' or nasal snuff
- ☐ vii) Chewing tobacco
- ☐ viii) None
- ☐ ix) 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 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)	☐	☐	☐	☐	☐	☐	☐

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

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

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

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

E40. During a typical week, how many minutes on average do you do the following types of exercise?

i) Vigorous exercise (breathing hard, heart beats rapidly).
For example: running, aerobics, martial arts, fast swimming, or a team sport such as football or hockey ☐☐☐ minutes per week

ii) Moderate exercise (heart rate increases slightly, but is not exhausting).
For example: fast walking or gentle cycling ☐☐☐ minutes per week

iii) Muscle strengthening activities
For example: lifting weights, push-ups and sit-ups, heavy gardening or yoga ☐☐ times per week

E41. On average, how much time do you spend outdoors?

i) 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
☐ Five or more hours per day	☐ Five or more hours per day

SECTION F - YOUR WELLBEING

F1. How many close friends do you have (other than your partner)?

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 or more

F2. Overall, how would you rate your relationships with your close friends?

☐ Poor ☐ Fair ☐ Good ☐ Excellent

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

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 **one month, as a result of your child's health**, 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	☐	☐	☐	☐	☐
l) I feel isolated from others	☐	☐	☐	☐	☐
m) I have trouble getting support from others	☐	☐	☐	☐	☐
n) It is hard to find time for social activities	☐	☐	☐	☐	☐
o) I do not have enough energy for social activities	☐	☐	☐	☐	☐

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	☐	☐	☐	☐	☐
t) I have trouble remembering what I was just thinking	☐	☐	☐	☐	☐
u) I feel that others do not understand my family's situation	☐	☐	☐	☐	☐
v) It is hard for me to talk about my child's health with others	☐	☐	☐	☐	☐
w) It is hard for me to tell doctors and nurses how I feel	☐	☐	☐	☐	☐
x) I worry about whether or not my child's medical treatments are working	☐	☐	☐	☐	☐
y) I worry about the side effects of my child's medications/medical treatments	☐	☐	☐	☐	☐
z) I worry about how others will react to my child's condition	☐	☐	☐	☐	☐
aa) I worry about how my child's illness is affecting other family members	☐	☐	☐	☐	☐
bb) I worry about my child's future	☐	☐	☐	☐	☐

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

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.

How happy are you with... (For example, 'Never happy', 'Often happy' etc)	Never	Some-times	Often	Almost always	Always	N/A
a) How much information was provided to you about your child's diagnosis?	☐	☐	☐	☐	☐	☐
b) How much information was provided to you about the treatment and course of your child's health condition?	☐	☐	☐	☐	☐	☐
c) How much information was provided to you about the side effects of your child's treatment?	☐	☐	☐	☐	☐	☐

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 **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?	☐	☐	☐	☐	☐	☐

F7 continued...

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

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

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'

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

b) I still enjoy the things I used to enjoy

- ☐ Definitely as much
- ☐ Not quite so much
- ☐ Only a little
- ☐ Hardly at all

c) I get a sort of frightened feeling as if something awful is about to happen

- ☐ Very definitely and quite badly
- ☐ Yes, but not too badly
- ☐ A little, but it doesn't worry me
- ☐ Not at all

d) I can laugh and see the funny side of things

- ☐ As much as I always could
- ☐ Not quite so much now
- ☐ Definitely not so much now
- ☐ Not at all

e) Worrying thoughts go through my mind

- ☐ A great deal of the time
- ☐ A lot of the time
- ☐ From time to time, but not too often
- ☐ Only occasionally

f) I feel cheerful

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

g) I can sit at ease and feel relaxed

- ☐ Definitely
- ☐ Usually
- ☐ Not often
- ☐ Not at all

h) I feel as if I am slowed down

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

F9 continued...

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

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

j) I have lost interest in my appearance

- ☐ Definitely
- ☐ I don't take as much care as I should
- ☐ I may not take quite as much care
- ☐ I take just as much care as ever

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

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

l) I look forward with enjoyment to things

- ☐ As much as I ever did
- ☐ Rather less than I used to
- ☐ Definitely less than I used to
- ☐ Hardly at all

m) I get sudden feelings of panic

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

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

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

Questions F10, F11 and F12 have been intentionally removed.

F13. These questions ask you about **your** feelings about your child's cleft. To what extent are each of these statements true of your feelings over the last **six months?**

	Never	Almost never	Some-times	Often	Almost always
a) I feel that the cleft has dominated my experience of having a baby	☐	☐	☐	☐	☐
b) I feel that it is my fault that my baby has a cleft	☐	☐	☐	☐	☐
c) I struggle to come to terms with my baby's cleft	☐	☐	☐	☐	☐

F13 continued...	Never	Almost never	Some-times	Often	Almost always
d) I worry that I am unable to care for my baby because of the cleft	☐	☐	☐	☐	☐
e) I worry about other health problems my baby may have	☐	☐	☐	☐	☐
f) I worry that the cleft will affect my relationship with my baby	☐	☐	☐	☐	☐
g) I feel optimistic about my baby's future	☐	☐	☐	☐	☐

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

F14.	Yes	Some-times	Not yet
a) Does your baby sometimes make throaty or gurgling sounds?	☐	☐	☐
b) Does your baby make cooing sounds such as "ooo", "gah", and "aah"?	☐	☐	☐
c) When you speak to your baby, does he/she make sounds back to you?	☐	☐	☐
d) Does your baby smile when you talk to him/her?	☐	☐	☐
e) Does your baby chuckle softly?	☐	☐	☐
f) After you have been out of sight, does your baby smile or get excited when he/she sees you?	☐	☐	☐

F15.	Yes	Some-times	Not yet
a) While your baby is on his/her back, do they wave their arms and legs, wiggle, and squirm?	☐	☐	☐
b) When your baby is on his/her tummy, do they turn their head to the side?	☐	☐	☐
c) When your baby is on his/her tummy, do they hold their head up longer than a few seconds?	☐	☐	☐
d) When your baby is on his/her back, do they kick their legs?	☐	☐	☐
e) After holding his/her head up while on their tummy, does your baby lay their head back down on the floor, rather than let it drop or fall forward?	☐	☐	☐
f) While your baby is on his/her back, do they move their head from side to side?	☐	☐	☐

F16.	Yes	Some-times	Not yet
a) Is your baby's hand usually tightly closed when he/she is awake?	☐	☐	☐
b) Does your baby grasp your finger if you touch the palm of his/her hand?	☐	☐	☐
c) When you put a toy in his/her hand, does your baby hold it in his/her hand briefly?	☐	☐	☐
d) Does your baby touch his/her face with their hands?	☐	☐	☐
e) Does your baby hold his/her hands open or partly open when he/she is awake?	☐	☐	☐
f) Does your baby grab or scratch at his/her clothes?	☐	☐	☐

F17.	Yes	Some-times	Not yet
a) Does your baby look at objects that are 8-10 inches away?	☐	☐	☐
b) When you move around, does your baby follow you with his/her eyes?	☐	☐	☐
c) When you move a toy slowly from **side to side** in front of your baby's face (about 10 inches away) does your baby follow the toy with his/her eyes?	☐	☐	☐
d) When you move a small toy **up and down** slowly in front of your baby's face (about 10 inches away), does your baby follow the toy with his/her eyes?	☐	☐	☐
e) When you hold your baby in a sitting position, does he/she look at a toy (about the size of a cup or a rattle) that you place on the table or floor in front of him/her?	☐	☐	☐
f) When you dangle a toy above your baby while he/she is lying on his/her back, do they wave their arms towards the toy?	☐	☐	☐

F18	Yes	Some-times	Not yet
a) Does your baby sometimes try to suck, even when he/she's not feeding?	☐	☐	☐
b) Does your baby cry when he/she is hungry, wet, tired, or wants to be held?	☐	☐	☐
c) Does your baby smile at you?	☐	☐	☐
d) When you smile at your baby, does he/she smile back?	☐	☐	☐
e) Does your baby watch his/her hands?	☐	☐	☐
f) When your baby sees the breast or the bottle, does he/she seem to know he/she is about to be fed?	☐	☐	☐

F19. a) Did your baby pass the newborn hearing screening test? If no, please explain.

☐ Yes ☐ No

b) Does your baby move both hands and both legs equally well? ☐ Yes ☐ No

c) Does either parent have a family history of childhood deafness, hearing impairment, or vision problems?

☐ Yes ☐ No

d) Has your baby had any medical problems? If yes, please explain.

☐ Yes ☐ No

e) Do you have concerns about your baby's behaviour (for example, eating, sleeping)? If yes, please explain.

☐ Yes ☐ No

f) Does anything about your baby worry you? If yes, please explain.

☐ Yes ☐ No

SECTION G - FURTHER INFORMATION

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

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
- ☐ b) Irregular periods
- ☐ c) Periods lasting longer than one week
- ☐ d) Menstrual pains
- ☐ e) Heavy bleeding
- ☐ f) Anaemia

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

- ☐ a) Condom
- ☐ b) Diaphragm
- ☐ c) Intrauterine Device (IUD) / coil
- ☐ d) Hormone Intrauterine Device (IUD) / coil
- ☐ e) Hormone injection
- ☐ f) Pill
- ☐ g) Mini pill
- ☐ h) Spermicide
- ☐ i) Withdrawal
- ☐ j) None
- ☐ k) Other

If other, 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
- ☐ 1-3 years
- ☐ 4-6 years
- ☐ 7-9 years
- ☐ 10 years or more
- ☐ Not applicable

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

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? ☐☐ times

G7. How many (in numbers) of these pregnancies ended in... **(Answer all that apply)**

☐ i) Live birth - full term ☐ ii) Still birth ☐ iii) Premature birth

☐ iv) Miscarriage ☐ v) Ectopic pregnancy ☐ vi) Termination

☐ vii) This is my first/only pregnancy **(Cross box if this answer applies to you)**

G8. If applicable, how were your child(ren) delivered?

a) This pregnancy (Cross one box only)

☐ i) Vaginal delivery
☐ ii) Emergency caesarean/c-section
☐ iii) Planned caesarean/c-section
☐ iv) Other assisted methods

b) Past pregnancies (Cross all that apply)

☐ i) Vaginal delivery
☐ ii) Emergency caesarean/c-section
☐ iii) Planned caesarean/c-section
☐ iv) Other assisted methods

G9. a) Was this pregnancy planned? ☐ Yes ☐ No

b) If yes, approximately how long did it take you to get pregnant? ☐☐ months ☐☐ years

G10. Did you have an amniocentesis (amnio) performed for this pregnancy? ☐ Yes ☐ No ☐ Don't know

G11. Did you experience any of these problems **during this pregnancy?**

		i) During the first three months of pregnancy		**ii) Rest of the pregnancy**
a) Inflammation of the bladder or kidneys	☐Yes ☐No	Medication used (if known)	☐Yes ☐No	Medication used (if known)
b) A heavy cold	☐Yes ☐No	Medication used (if known)	☐Yes ☐No	Medication used (if known)
c) Influenza/Flu	☐Yes ☐No	Medication used (if known)	☐Yes ☐No	Medication used (if known)

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

G11. Continued...	i) During the first three months of pregnancy	ii) Rest of the pregnancy
q) Jaundice	☐ Yes ☐ No — Medication used (if known)	☐ Yes ☐ No — Medication used (if known)
r) Syphilis	☐ Yes ☐ No — Medication used (if known)	☐ Yes ☐ No — Medication used (if known)
s) Pre-eclampsia	☐ Yes ☐ No — Medication used (if known)	☐ Yes ☐ No — Medication used (if known)
t) Toxoplasmosis	☐ Yes ☐ No — Medication used (if known)	☐ Yes ☐ No — 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

☐ Yes
☐ No

If yes, please specify:

ii) Rest of the pregnancy

☐ Yes
☐ No

If yes, please specify:

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

i) ☐ Yes ☐ No

ii) If yes, length of stay (days) ☐☐

b) Rest of the pregnancy

i) Yes ☐ No ☐

ii) If yes, length of stay (days) ☐☐

c) What was the cause of your hospital admission?

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 pregnancy?

i) During the first three months of pregnancy	**ii) Rest of the pregnancy**
☐ Yes ☐ No ☐ Don't know	☐ Yes ☐ No ☐ Don't know

Although we have asked similar questions earlier in this questionnaire, the following questions relate to when you were pregnant with your child who was born with a cleft.

G16. a) Did you smoke during this pregnancy? ☐ Yes ☐ No

b) If yes, when? (Cross **all** that apply) ☐ i) 0 - 3 months ☐ ii) 4 - 9 months

c) If yes, how many did you smoke per 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 **all** that apply) ☐ i) 0 - 3 months ☐ ii) 4 - 9 months

c) If yes, how much alcohol did you drink **per week? (See image on page 28 to help answer the question)**

☐ 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	

G18. a) Did you drink caffeinated drinks (such as tea, coffee and fizzy drinks) during this pregnancy? ☐ Yes ☐ No

b) If yes, when? (Cross **all** that apply) ☐ i) 0 - 3 months
☐ ii) 4 - 9 months

c) If yes, how often did you drink caffeinated drinks?

☐ Less than once a month
☐ One or two cups a week
☐ One or two cups a day
☐ Three to five cups a day
☐ More than five cups a day

G19. a) Did you use drugs during this pregnancy? ☐ Yes ☐ No

b) If yes, when? (Cross **all** that apply) ☐ i) 0 - 3 months
☐ ii) 4 - 9 months

c) If yes, how often did you use them? (Cross **all** that apply)

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

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

G20. What is the highest educational qualification **your partner** has obtained? **(Cross one 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
- ☐ At home
- ☐ Intern/apprentice
- ☐ Military Service
- ☐ Unemployed/laid off
- ☐ Rehabilitation/disabled
- ☐ Employed in public sector
- ☐ Employed in private sector
- ☐ Self-employed
- ☐ 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.

SECTION Z

Z1. This questionnaire was completed by:

a) Baby's biological mother ☐

b) Baby's step mother ☐

c) Baby's adoptive / foster mother ☐

d) Someone else (please cross box and describe) ☐ [ ]

Z2. Do you live in the same house as the baby? ☐ 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 **baby's** date of birth DD MM YYYY [ ][ ] / [ ][ ] / [ ][ ][ ][ ]

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE.

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

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

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University of Bristol
Oakfield House
Oakfield Grove
Bristol, BS8 2BN

Office use only ☐

www.cleftcollective.org.uk/bristol