



Dr Palak Trivedi  
**The UK PSC Study**

Recruitment centre: «Recruiting\_hospital»

**Research Centre:**  
 Dept. of Medical Genetics  
 Lv 6, Addenbrooke's Treatment Centre  
 Cambridge Biomedical Campus  
 Hills Rd  
 Cambridge  
 CB2 0QQ

### Paediatric Participant Questionnaire, Version 1

#### ***Research study into the genetic causes of Primary Sclerosing Cholangitis and childhood autoimmune liver disease***

Parents/guardians of child participants: please could you complete this on your child's behalf. If your child is aged 11 or over, they are welcome to complete the *UK PSC Participant Questionnaire* (version 3) themselves, with your support if they need it.

*Please tick the boxes which apply.*

**1)** What is your child's date of birth? \_\_\_\_\_

**2)** What is your child's sex? Male ☐ Female ☐

**3)** Does your child have Inflammatory Bowel Disease? Yes ☐ No ☐ Not Sure ☐

**4)** If yes do they have: Ulcerative Colitis ☐ Crohn's ☐ Not Sure ☐

**5a)** Has your child lived in accommodation that is occupied with pets? Yes ☐ No ☐

**5b)** If yes please could you indicate which pets and at what ages of their life?

Type of animal	Child's age

6) Sometimes the genes involved in causing diseases like autoimmune liver disease are different for different ethnic groups. Knowing your child's ethnic category will help us to analyse the results of this study. Please indicate your child's ethnic category by ticking the most appropriate box.

NATIONAL CODE		PLEASE TICK
<b>WHITE</b>		
A	BRITISH	
B	IRISH	
C	ANY OTHER WHITE BACKGROUND	
<b>MIXED</b>		
D	WHITE AND BLACK CARIBBEAN	
E	WHITE AND BLACK AFRICAN	
F	WHITE AND ASIAN	
G	ANY OTHER MIXED BACKGROUND	
<b>ASIAN OR ASIAN BRITISH</b>		
H	INDIAN	
J	PAKISTANI	
K	BANGLADESHI	
L	ANY OTHER ASIAN BACKGROUND	
<b>BLACK OR BLACK BRITISH</b>		
M	CARIBBEAN	
N	AFRICAN	
P	ANY OTHER BLACK BACKGROUND	
<b>OTHER ETHNIC GROUPS</b>		
R	CHINESE	
S	ANY OTHER ETHNIC GROUP	
Z	NOT STATED	

7) What is your child's current weight? \_\_\_\_\_ (Answer in stones and pounds or kilograms)

8) How tall is your child? \_\_\_\_\_ (Either answer in metres/cms or feet and inches).

9) Please indicate the areas that your child has ever lived in:

Country of Birth \_\_\_\_\_

Areas Lived	Location (Post Code)	Duration of stay in that area

**10)** If your child has had symptoms from their autoimmune liver disease, how long did it take for them to be diagnosed?

\_\_\_\_\_ (Years and Months)

**11)** Has your child been given enough information about their childhood autoimmune liver disease?

Yes ☐ No ☐ Not sure ☐

**12a)** Do other members of your child's family have autoimmune liver disease?

Yes ☐ No ☐ Not sure ☐

**12b)** If yes, please indicate, by ticking in the box below, which other members of your child's family have autoimmune liver disease.

RELATIVE WITH PSC OR CHILDHOOD AILD	TICK
GRANDMOTHER	
GRANDFATHER	
FATHER	
MOTHER	
MATERNAL AUNT	
MATERNAL UNCLE	
PATERNAL AUNT	
PATERNAL UNCLE	
BROTHER	
SISTER	
OTHERS	

**12c)** How many brothers and sisters does your child have (**alive or dead**)?

Brothers \_\_\_\_\_ Sisters \_\_\_\_\_

**13a)** Do other members of your child's family have Inflammatory Bowel Disease?

Yes ☐ No ☐ Not Sure ☐

**13b)** If yes, please indicate, by ticking in the box below, which other family members have Inflammatory Bowel disease

RELATIVE WITH IBD	TICK
GRANDMOTHER	
GRANDFATHER	
FATHER	
MOTHER	
MATERNAL AUNT	
MATERNAL UNCLE	

PATERNAL AUNT	
PATERNAL UNCLE	
BROTHER	
SISTER	
OTHERS	

**14)** Do members of your child's family have Colorectal Cancer or have they had it in the past?

Yes ☐ No ☐ Not Sure ☐

**15)** Does your child suffer from any of the following medical conditions? Please tick all that apply

CONDITION	TICK
A) SYSTEMIC LUPUS ERYTHEMATOSIS (SLE)	
B) OVERACTIVE OR UNDERACTIVE THYROID DISEASE	
C) INSULIN DEPENDENT DIABETES STARTING FROM YOUNG AGE	
D) SJOGREN'S SYNDROME	
E) SCLERODERMA	
F) COELIAC DISEASE	

**16)** Has your child had any operations?

Yes ☐

No ☐

If yes, please detail below

OPERATION	DATE

**17)** How old was your child when he/she was first diagnosed with autoimmune liver disease?

\_\_\_\_\_ years **(Please leave blank if not sure)**

**18)** If your child has inflammatory bowel disease, how old were they when they first had it?

\_\_\_\_\_ years **(Please leave blank if not sure)**

**19)** When your child was first diagnosed with autoimmune liver disease, did they have any of the following symptoms?

SYMPTOM	TICK
A) ITCHING	
B) EXCESSIVE TIREDNESS	
C) DISCOMFORT IN THE LIVER AREA (THE RIGHT-SIDED, UPPER PART OF THE TUMMY)	
D) ACHING OF THE BONES	
E) ASCITES (FLUID INSIDE THE TUMMY)	
F) BLEEDING FROM VARICES (SWOLLEN VEINS AT THE BOTTOM END OF THE GULLET)	
G) JAUNDICE (YELLOW DISCOLOURATION AFFECTING THE WHITE OF THE EYE)	
H) HEPATIC ENCEPHALOPATHY (CONFUSION OWING TO LIVER DISEASE)	
I) NO SYMPTOMS (ONLY THE LIVER TESTS WERE ABNORMAL)	
J) OTHER SYMPTOMS	

**20a)** Has your child had a liver transplant?

Yes ☐

No ☐

**20b)** If yes, when was it performed? (DD/MM/YYYY) \_\_\_\_\_

**Please answer questions 21-23, if your child has *not* had a liver transplant. Otherwise please go to question 24.**

**21)** If your child has **not** had a liver transplant, do they have any of the following symptoms now? How long have they had them?

SYMPTOM	TICK	DURATION
A) ITCHING		
B) EXCESSIVE TIREDNESS		
C) DISCOMFORT IN THE LIVER AREA (THE RIGHT-SIDED, UPPER PART OF THE TUMMY)		
D) ACHING OF THE BONES		
E) ASCITES (FLUID INSIDE THE TUMMY)		
F) BLEEDING FROM VARICES (SWOLLEN VEINS AT THE BOTTOM END OF THE GULLET)		
G) JAUNDICE (YELLOW DISCOLOURATION AFFECTING THE WHITE OF THE EYE)		
H) HEPATIC ENCEPHALOPATHY (CONFUSION OWING TO LIVER DISEASE)		

I) NO SYMPTOMS		
J) OTHERS		

**22)** Is your child receiving any of the following medications for their autoimmune liver disease? Please tick all that apply

MEDICATION	TICK
A) URSODEOXYCHOLIC ACID (URSO)? PLEASE STATE THE DOSE	
B) CHOLESTYRAMINE?	
C) RIFAMPICIN?	
D) PREDNISOLONE	
E) AZATHIOPRINE	
F) MYCOPHENOLATE MOFETIL	
G) CYCLOSPORINE	
H) TACROLIMUS	

**23)** Is your child waiting for a liver transplant?

Yes ☐

No ☐

**All respondents: please answer the remaining questions below**

**24)** Has your child ever suffered from a cancer?

Yes ☐

No ☐

If yes please provide details below

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**25)** What is the name of the consultant seeing your child for their autoimmune liver disease?

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**Many thanks for filling this in.**

*If you have any **questions** or **queries** regarding the **completion** of this questionnaire please contact:  
the UK PSC team ([ukpsc@uhb.nhs.uk](mailto:ukpsc@uhb.nhs.uk); Tel: 0121 371 8101).*

**Please return your completed questionnaire, in the freepost envelope provided, to:**

**The UK PSC Study,**  
Box 238  
Dept. of Medical Genetics  
Lv 6 Addenbrooke's Treatment Centre,  
Hills Rd,  
Cambridge, CB2 0QQ