



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

Participant Questionnaire, Version 3

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

We would be grateful if you could complete this questionnaire. Please tick the boxes which apply.

1) What is your date of birth? _____

2) What is your sex? Male ☐ Female ☐

3) Do you have Inflammatory Bowel Disease? Yes ☐ No ☐ Not Sure ☐

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

5a) Do you or have you ever smoked? Yes ☐ No ☐

5b) If you have smoked then please list the dates between which you smoked tobacco

From ____/____/____ To ____/____/____

5c) How many cigarettes per day do or did you smoke? _____

6a) Do you drink alcohol? Yes ☐ No ☐

6b) If yes, how many units of alcohol do you drink per week? _____

7a) Do you drink coffee? Yes ☐ No ☐

7b) If yes, how many cups do you drink per day? _____

8a) Have you lived in accommodation that is occupied with pets? Yes ☐ No ☐

8b) If yes please could you indicate which pets and at what ages of your life?

Type of animal	Your age

9) Sometimes the genes involved in causing a disease like PSC are different for different ethnic groups. Knowing your ethnic category will help us to analyse the results of this study. Please indicate your ethnic category by ticking the most appropriate box.

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

10) What is your current weight? _____ (Answer in stones and pounds or kilograms)

16b) 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	

17) Do members of your family have Colorectal Cancer or have they had it in the past?

Yes ☐ No ☐ Not Sure ☐

18a) How many children do you have?

SONS (Please indicate how many)	DAUGHTERS (Please indicate how many)

18b) Do they have any illnesses? If so please describe them all in the box below:

--

19) Do you suffer from any of the following medical conditions (you'll know if you have it!)? 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	

20) Have you had any operations?
If yes, please detail below

Yes

☐

No

☐

OPERATION	DATE

21) How old were you when you were first diagnosed with PSC?

_____ years **(Please leave blank if not sure)**

22) If you have inflammatory bowel disease, how old were you when you first had it?

_____ years **(Please leave blank if not sure)**

23) When you were first diagnosed with PSC, did you 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:	

24a) Have you had a liver transplant?

Yes

☐

No

☐

24b) If yes, when was it performed? (DD/MM/YYYY)_____

Please answer questions 25-27, if you have *not* had a liver transplant.
Otherwise please go to question 28.

25) If you have **not** had a liver transplant, do you have any of the following symptoms now? How long have you 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		

26) Are you receiving any of the following medications for PSC? 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	

27) Are you waiting for a liver transplant?

Yes ☐ No ☐

All respondents: please answer the remaining questions below

28) Have you ever suffered from a cancer?

Yes

☐

No

☐

If yes please provide details below

29) What is the name of the consultant seeing you for PSC?

.....

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; 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