



**The UK PSC Study
Research Centre:**

Dept. of Medical Genetics
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Cambridge
CB2 0QQ
Tel: 0121 371 8101
ukpsc@uhb.nhs.uk

<UKPSC participant ID>

Name

Address1

Address2

Address3

Address4

Address5

Date

Dear _____,

Thank you for your support of the UK PSC Study. We are writing to you to let you know that as part of the study, we plan to collect information about your health and health care usage over the long term, through your medical records.

By doing this, we will be able to obtain data on any changes to your health condition or hospital visits directly from your medical notes more efficiently. This means we will ask you or your clinical care team to complete fewer health update questionnaires.

Your information will be pooled among all UK PSC participants. It will help to give us a richer picture of what causes PSC and childhood autoimmune liver disease to progress over time. It may also enable us to develop new, effective treatments.

We may request data from your hospital and GP service, but NHS Digital will provide most of it (if you live in England).

NHS Digital (<https://digital.nhs.uk/>) is a national provider of information, data and IT systems for England. Its role is:

- To operate and develop IT systems
- To collect, process and publish data
- To ensure that organisations meet information and security standards, so that patient data is kept safe

To obtain clinical information about you, we will need to share some of your personal details with NHS Digital or your hospital, such as your name, date of birth and NHS number. This data will be supplied using a secure system.

If you prefer us not to access your information in this way, please let us know either by email (ukpsc@uhb.nhs.uk), phone (0121 371 8101) or by returning the enclosed opt-out form in the freepost envelope provided.

For more information, including on opting out from this type of data access or withdrawing from the study, see www.uk-psc.com/patients or contact the UK PSC Project Manager, <Insert name>, (0121 371 8101; ukpsc@uhb.nhs.uk).

Thank you again for your participation in the **UK PSC Study**.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Palak Trivedi', with a long, sweeping horizontal stroke extending to the left.

Dr Palak Trivedi
Chief Investigator – UK PSC