

5 February 2018

Dear Research Ethics Committee,

**UK PSC access to clinical data from NHS data centres**

Following a consultation with our committee, I am writing to express PSC Support's enthusiastic backing for UK PSC's plan to access clinical data from NHS data centres, and for their planned communications with study participants.

UK PSC depends for its research value on the accuracy, comprehensiveness and timeliness of the data it collects on its participants. Accessing data at regular intervals from NHS Data Centres will enable the study to profile adults with PSC and children with autoimmune liver disease, and to monitor their health outcomes over the long term. The team will also be able to run the study more efficiently and cost-effectively.

We also support the use of an opt-out system, whereby existing study participants can choose to be excluded from data downloads from these NHS Data Centres. We have reviewed the UK PSC participant Information letters and webpages drafted by UK PSC ([www.uk-psc.com/patients](http://www.uk-psc.com/patients)). They provide clear and comprehensive information for participants on the data access process and the provisions for fair processing. They also explain how to opt-out from this data linkage or to withdraw completely from the study.

We would also be happy to inform participants of this initiative via our newsletters and website.

PSC is a leading indicator for liver transplant and no effective therapies currently exist for this disease. We are grateful for the efforts of the UK PSC consortium to move forward research in this area and for their long term commitment to working in partnership with us, the leading UK charity for PSC patients.

As a member of the UK PSC Steering Group, I am able to provide a patient voice to inform any planned developments to the UK PSC Study. Our charity is keen to support this vital initiative to improve the quality and timeliness of the clinical data collected for UK PSC.

Yours sincerely,



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