



GDPR Transparency Information
(To be sent with PIS)

University of Cambridge and Cambridge University Hospitals NHS Foundation Trust are the sponsors for this study, both based in the United Kingdom. We will be using information from you and your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. University of Cambridge and Cambridge University Hospitals NHS Foundation Trust will keep identifiable information about you for 10 years after the study has finished. Non-identifiable information about you (such as the results of medical investigations) will be retained indefinitely for further analysis in future, ethically-approved studies.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting the UK-PSC Project Manager at the following email address: ukpsc@uhb.nhs.uk

The hospital who has sent this letter and University of Cambridge and Cambridge University Hospitals NHS Foundation Trust will collect information from you and your medical records for this research study in accordance with our instructions.

The hospital who has sent this letter and University of Cambridge and Cambridge University Hospitals NHS Foundation Trust will use your name, NHS number and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from University of Cambridge, Cambridge University Hospitals NHS Foundation Trust and regulatory organisations may look at your medical and research records to check the accuracy of the research study.

The hospital who has sent this letter will pass these details to University of Cambridge and Cambridge University Hospitals NHS Foundation Trust along with the information collected from you and your medical records. The only people in University of Cambridge and Cambridge University Hospitals NHS Foundation Trust who will have access to information that identifies you will be people who need to contact you to update you about the study, contact you about other clinical trials (if you have explicitly consented to receive this information) or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name, NHS number or contact details.

University of Cambridge and Cambridge University Hospitals NHS Foundation Trust will keep identifiable information about you from this study for 10 years after the study has finished. Non-identifiable information about you (such as the results of medical investigations) will be retained indefinitely for further analysis in future, ethically-approved studies.

For patients who have signed Informed Consent Form v3 (in use since May 2016) or a newer version, the University of Cambridge and Cambridge University Hospitals NHS Foundation Trust will collect information about you for this research study from:

- [NHS Digital](https://digital.nhs.uk/) (participants in England) - <https://digital.nhs.uk/>
- [The Information Services Division, NHS National Services Scotland](http://www.isdscotland.org/) - <http://www.isdscotland.org/>
- [NHS Wales Informatics Service](http://www.wales.nhs.uk/sitesplus/956/home) - <http://www.wales.nhs.uk/sitesplus/956/home>
- [The Health and Social Care Board Northern Ireland](http://www.hscboard.hscni.net/) - <http://www.hscboard.hscni.net/>

This information will include your name, NHS number (or CHI number if you live in Scotland), contact details, and health information, which is regarded as a special category of information. We will use this information to update the clinical information about you as we wish to monitor your PSC over the long term, as this will give us a better picture of how PSC and childhood autoimmune liver disease progress and why some people develop more problems and others don't.