



**GDPR Transparency Information**  
*(To be published on the UK-PSC.com website)*

As a NHS organisation we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. 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.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the [UK Policy Framework for Health and Social Care Research](#).

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Our Data Protection Officer is Michelle Ellerbeck and you can contact them at [michelle.ellerbeck@addenbrookes.nhs.uk](mailto:michelle.ellerbeck@addenbrookes.nhs.uk).

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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.

If you prefer us not to access your information in this way, please let us know either by email ([ukpsc@uhb.nhs.uk](mailto:ukpsc@uhb.nhs.uk)) or phone (0121 371 8101).

When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the [UK Policy Framework for Health and Social Care Research](#). This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.