

# UKITP STUDY INFORMED CONSENT AGREEMENT (4.3)



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## Study Informed Consent Agreement UK Adult Idiopathic Thrombocytopenic Purpura (ITP) Registry

1. I confirm that I have read and understand the Prospective Participant Overview of the UK Adult Idiopathic Thrombocytopenic Purpura (ITP) Registry dated 22.02.2017 (version 3.1) and have had the opportunity to address any questions or concerns that I had concerning the study  *Please initial boxes*
2. I understand that my participation is voluntary and that I am free to withdraw from the study at any time without giving any reason and without my medical care or legal rights being affected.
3. I understand that ITP-related information from my medical notes may be extracted by responsible individuals comprising my clinical care team or the chief investigator's study team. I give permission for these individuals to have access to my medical records.
4. As part of keeping my records complete and up-to-date at the registry, I give permission to the chief investigator's study team to obtain study-related information:
  - a. From my Summary Care Records
  - b. By contacting my General Practitioner
  - c. Through the Data Linkage Services provided by the NHS's Health and Social Care Information Centre
5. I allow the study coordinator for the UK Adult ITP Registry to share coded data with GlaxoSmithKline and the Paediatric and Adult Intercontinental Registry on Chronic ITP (PARC-ITP) Study during the investigation. I understand that, as part of these collaborations, data will be shared with researchers in non-European Economic Area (EEA) countries which may not have laws protecting patient privacy to the same extent as the UK Data Protection Act or European Law. Within these constraints, I am aware that study personnel will take all reasonable steps to protect my privacy.
6. I agree to donate 50mls blood on up to four occasions for the immune profiling study. I understand that during these studies, cells or whole blood will be transported to either the NHS-Blood & Transplant unit, Filton, Bristol; GlaxoSmithKline laboratories, and other 3rd parties at GSK's discretion. Remaining samples will be destroyed at the end of the study.
7. I agree to take part in the U.K. Adult Idiopathic Thrombocytopenic Purpura (ITP) Registry

_____	_____	_____
Name of Patient	Date	Signature
_____	_____	_____
Name of Person Taking Consent (if different from researcher)	Date	Signature
_____	_____	_____
Researcher	Date	Signature