

UKITP STUDY INFORMED CONSENT AGREEMENT (4.43)



Barts Health NHS Trust
The Royal London Hospital
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Centre for Haematology
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Study Informed Consent Agreement

UK Adult Idiopathic Thrombocytopenic ~~Purpura~~ (ITP) Registry

- 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 3.2+) and have had the opportunity to address any questions or concerns that I had concerning the study
- 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.
- 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.
- 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:
 - From my Summary Care Records
 - By contacting my General Practitioner
 - Through the Data Linkage Services provided by the NHS's Health and Social Care Information Centre
- The UK ITP Registry may collaborate with fellow researchers outside of Queen Mary University of London if expertise and facilities not available

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Version 4.4 – 16th May 2018

UK ITP Registry
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Note: Original kept with hospital notes; 1 Copy for patient; 1 Copy for data manager

Revised 22nd February 2017

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at the University are required (e.g. certain DNA analysis, bioinformatics, etc). If this collaboration is deemed necessary, I agree that the UK ITP Registry may enter into a data sharing agreement with these researchers where anonymised information may be shared for a defined period of time.

6. I agree to take part in the UK ITP Registry.

7. I agree to donate 4-8 ml of blood on one occasion for genetic analysis. Blood will be stored at The Royal London Hospital and blood remaining post-analysis will be destroyed in line with the Human Tissue Authority.

Royal London Hospital patients only:

8. I agree to donate four blood samples of 50ml (10 teaspoons) over a six month period for the sub-study looking at the cells in my blood (optional).

~~5. I allow the study coordinator for the UK Adult ITP Registry to share coded data with GlaxoSmithKline and the Paediatric and Adult Interecontinental 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.~~

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

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