

UKITP STUDY INFORMED CONSENT AGREEMENT (4.43)



Barts Health NHS Trust  
The Royal London Hospital  
Pathology and Pharmacy Building  
80 Newark Street, London E1 2ES

Centre for Haematology  
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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 3.2+) and have had the opportunity to address any questions or concerns that I had concerning the study
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. The UK ITP Registry may collaborate with fellow researchers outside of Queen Mary University of London if expertise and facilities not available

Please initial boxes

  
  
  
  
  
  
  



Version 4.4 – 16<sup>th</sup> May 2018

UK ITP Registry  
IRAS ID: 92703  
Barts Health NHS Trust  
The Royal London Hospital  
Pathology and Pharmacy Building  
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Note: Original kept with hospital notes; 1 Copy for patient; 1 Copy for data manager

Revised 22<sup>nd</sup> 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.~~

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

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