

UKITPR STUDY INFORMED CONSENT AGREEMENT (5.0)

Site address and
contact details here



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details here

Study Informed Consent Agreement

UK Adult Idiopathic Thrombocytopenia (ITP) Registry

Please initial
boxes

1. I confirm that I have read and understand the Prospective Participant Overview of the UK Adult Idiopathic Thrombocytopenia (ITP) Registry (version 3.3) and have had the opportunity to address any questions or concerns that I had regarding 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 records 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. From my General Practitioner ☐
 - c. Through the Data Linkage Services provided by the NHS's Health and Social Care Information Centre or NHS Digital. ☐
5. The UK ITP Registry may collaborate with fellow researchers outside of Queen Mary University of London if expertise and facilities not available 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. ☐

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7. I agree to donate 4-8 ml of blood on one occasion for genetic material extraction to allow genetic analysis for causes, treatment responses and disease associations of ITP. Prior to genetic material extraction, blood will be stored at The Royal London Hospital. Following extraction, any blood remaining will be disposed of in line with the Human Tissue Authority. The donation of a blood sample may take place at a time after initial consent, according to practical convenience and considerations.

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- a. I consent to the storage of my blood or saliva in a research tissue bank for use in future studies.

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- b. I agree that the blood or saliva I have supplied may be used for future genetic research but not for research involving cloning or for the testing of inherited diseases without my express consent.

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- c. I am aware that I am free to withdraw my consent for the subsequent storage and use of my blood or saliva at any time.

☐

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).

☐

Name of Participant

Date

Signature

Name of researcher
taking consent

Date

Signature

Name of Research Site