

UKITPR STUDY INFORMED CONSENT AGREEMENT (6.1)

Site address and
contact details here



Insert Trust Logo here

Study Informed Consent Agreement

UK Adult Idiopathic Thrombocytopenia (ITP) Registry

Please initial
boxes

1. I confirm that I have read and understand the Participant Information Sheet of the UK Adult Immune Thrombocytopenia (ITP) Registry (version 5.1) 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 relevant sections of 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 this collaboration is 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 for genetic material extraction to allow genetic analysis including whole genome sequencing and RNA sequencing or any novel genomic technologies in the future. Prior to genetic material extraction, blood will be stored at The Royal London Hospital. The donation of a blood sample may take place at a time after initial consent, according to practical convenience and considerations.

☐

- a. I consent to the obtaining or transfer and storage of my previously obtained blood, or saliva in a research tissue bank for use in future studies.

☐

- b. I agree that the tissue as stated above may be used for genetic research

☐

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

☐

8. I agree that the samples I have donated and the information gathered about me can be stored for use in future medical research studies aimed at identifying the interactions between genes, the environment and disease.

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9. In the event that an abnormality that has significance for my care is picked up from tests carried out on my sample, I agree that my clinical care team or GP can be notified.

☐

Optional Sub-study – Platelet and Immunological Investigation:

10. I agree to donate four blood samples of 50ml (10 teaspoons) for the sub-study looking at the cells, metabolites, proteins in my blood.

☐

Name of Participant

Date

Signature

Name of researcher
taking consent

Date

Signature

Name of Research Site