

**UK ITP REGISTRY INITIAL INFORMATION SHEET (2.5)**



**Participant Name:**

**Date of Data Collection:**

**Registry Identification Code (RIC):**

Participant Details				
<b>Date of Birth:</b>	<b>Gender:</b> <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Uncertain			
<b>Ethnicity:</b>				
<table border="0" style="width: 100%;"> <tr> <td style="width: 50%; vertical-align: top;"> <b>White</b>  <input type="checkbox"/> English/Welsh/Scottish/Northern Irish/British  <input type="checkbox"/> Irish  <input type="checkbox"/> Gypsy or Irish Traveller  <input type="checkbox"/> Any other White background   <b>Mixed/Multiple ethnic groups</b>  <input type="checkbox"/> White and Black Caribbean  <input type="checkbox"/> White and Black African  <input type="checkbox"/> White and Asian  <input type="checkbox"/> Any other Mixed/Multiple ethnic background                 </td> <td style="width: 50%; vertical-align: top;"> <b>Asian/Asian British</b>  <input type="checkbox"/> Indian  <input type="checkbox"/> Pakistani  <input type="checkbox"/> Bangladeshi  <input type="checkbox"/> Chinese  <input type="checkbox"/> Any other Asian background   <b>Black/ African/Caribbean/Black British</b>  <input type="checkbox"/> African  <input type="checkbox"/> Caribbean  <input type="checkbox"/> Any other Black/African/Caribbean background   <b>Other ethnic group</b>  <input type="checkbox"/> Arab  <input type="checkbox"/> Any other ethnic group                 </td> </tr> </table>			<b>White</b> <input type="checkbox"/> English/Welsh/Scottish/Northern Irish/British <input type="checkbox"/> Irish <input type="checkbox"/> Gypsy or Irish Traveller <input type="checkbox"/> Any other White background  <b>Mixed/Multiple ethnic groups</b> <input type="checkbox"/> White and Black Caribbean <input type="checkbox"/> White and Black African <input type="checkbox"/> White and Asian <input type="checkbox"/> Any other Mixed/Multiple ethnic background	<b>Asian/Asian British</b> <input type="checkbox"/> Indian <input type="checkbox"/> Pakistani <input type="checkbox"/> Bangladeshi <input type="checkbox"/> Chinese <input type="checkbox"/> Any other Asian background  <b>Black/ African/Caribbean/Black British</b> <input type="checkbox"/> African <input type="checkbox"/> Caribbean <input type="checkbox"/> Any other Black/African/Caribbean background  <b>Other ethnic group</b> <input type="checkbox"/> Arab <input type="checkbox"/> Any other ethnic group
<b>White</b> <input type="checkbox"/> English/Welsh/Scottish/Northern Irish/British <input type="checkbox"/> Irish <input type="checkbox"/> Gypsy or Irish Traveller <input type="checkbox"/> Any other White background  <b>Mixed/Multiple ethnic groups</b> <input type="checkbox"/> White and Black Caribbean <input type="checkbox"/> White and Black African <input type="checkbox"/> White and Asian <input type="checkbox"/> Any other Mixed/Multiple ethnic background	<b>Asian/Asian British</b> <input type="checkbox"/> Indian <input type="checkbox"/> Pakistani <input type="checkbox"/> Bangladeshi <input type="checkbox"/> Chinese <input type="checkbox"/> Any other Asian background  <b>Black/ African/Caribbean/Black British</b> <input type="checkbox"/> African <input type="checkbox"/> Caribbean <input type="checkbox"/> Any other Black/African/Caribbean background  <b>Other ethnic group</b> <input type="checkbox"/> Arab <input type="checkbox"/> Any other ethnic group			
<b>Consent Date:</b>	<b>Date of last ITP-related clinic:</b>			
Clinical Information				
<b>Haematologist's name:</b>	<b>Haematologist's hospital:</b>			
<b>Was this participant diagnosed with ITP at your centre?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No				
<b>Was this participant referred to your centre for ITP care?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Information not available				
If yes to above:				
<b>Name of referrer:</b>	<b>Speciality of referrer:</b>	<b>Name of GP Practice or Hospital of referrer:</b>		
<b>Lifestyle Information-</b> questions in this section should be answered with values from time of diagnosis if possible. If answers aren't available at diagnosis, please give the measurements as close to diagnosis as possible.				
<b>Weight (kg):</b>	<b>kg</b>	<b>Height (cm):</b> <span style="float: right;"><b>cm</b></span>		

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<b>Date:</b>	<b>Date:</b>	
<b>Smoking status:</b> <input type="checkbox"/> No data available <input type="checkbox"/> Never smoked <input type="checkbox"/> Ex-smoker <input type="checkbox"/> Current smoker	<b>If ex or current smoker, daily consumption:</b> <input type="checkbox"/> Occasional <input type="checkbox"/> <10 a day <input type="checkbox"/> 11-20 a day <input type="checkbox"/> 21-40 a day <input type="checkbox"/> >40 a day	
<b>Date:</b>		
<b>Does the participant chew tobacco products?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No information available	<b>If yes, which chewing product is used?</b> <input type="checkbox"/> Other <input type="checkbox"/> Tobacco <input type="checkbox"/> Betel <input type="checkbox"/> Areca Nut	
<b>Date:</b>		
<b>Alcohol consumption:</b> <input type="checkbox"/> None <input type="checkbox"/> Occasional <input type="checkbox"/> <10 units per week <input type="checkbox"/> 11-20 units per week <input type="checkbox"/> 21-40 units per week <input type="checkbox"/> >40 units per week <input type="checkbox"/> Consumption not available	<b>Date:</b>	
<b>Bleeding events-</b> Please use headings provided in first row to guide completion of remaining rows		
<b>Type of Bleed</b>	<b>Severity of Bleed</b>	<b>Date of Bleed</b>
Bruise Cutaneous Bleeds Epistaxis Gastrointestinal bleeding Haematemesis Haematuria Haemoptysis Intracranial Haemorrhage (non-traumatic) Intracranial Haemorrhage (traumatic) Joint Bleeds Menorrhagia Muscle Bleeds Oral mucosal Other intra-ocular bleed Pulmonary haemorrhage Retinal Bleeds Subconjunctival Bleeds Uterine Bleeds Vitreous haemorrhage Other (Please Specify)	Mild- minor bruising/ bleeding and/or petechia that was resolved quickly and spontaneously.  Moderate- prolonged bleeding (e.g. epistaxis, extensive bruising, wet purpura) that did not require intervention.  Severe- e.g. requiring haemostatic intervention, transfusion, any intracranial haemorrhage or haemodynamic instability.	
e.g. Epistaxis	Moderate	01/01/2012

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<b>ITP Treatments</b>			
<b>Surgical treatments</b>			
<b>Has this participant had a splenectomy?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No		<b>If yes, type of splenectomy?</b> <input type="checkbox"/> Laparoscopic <input type="checkbox"/> Open <input type="checkbox"/> Not available	
<b>Medical ITP Treatments-</b> Please use headings provided in first row to guide completion of remaining rows			
Treatment	Dose	How long was this treatment given for? (days)	Date of Treatment
Anti-D	g		
Azathioprine	mg/day		
Cyclophosphamide	mg/day		
Cyclosporine	mg/week		
Danazol	mg/day		
Dapsone	mg		
Dexamethasone	mg/day		
Eltrombopag	mg/day		
IVIg	g/day		
Methylprednisolone	mg/day		
Mycophenolate	mg/day		
Prednisolone	mg/ day		
Rituximab	mg/m <sup>2</sup> /week		
Romiplostin	µg/kg/week		
Vinca Alkaloids	mg/week		



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<b>Co-Therapies</b>			
<b>Type of Co-therapy</b>	<b>Name of Treatment</b>	<b>Course</b>	<b>Start Date</b>
Anti-lipid Anti-hypertensive Anti-coagulant Thrombolysis Anti-fibrinolytic		One off Continuous Unknown	Leave blank if still on drug
<b>Co-morbidities</b>			
<b>Co-morbidity</b>		<b>Date of co-morbidity diagnosis</b>	
<b>Family History</b>			
<b>Family History of Cancer?</b>	<b>Site of cancer</b>	<b>Relationship to participant</b>	
<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Uncertain			
<b>Family History of Ischaemic Heart Disease?</b>	<b>Type of Ischaemic Heart Disease</b>	<b>Relationship to participant</b>	
<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Uncertain	<input type="checkbox"/> Stable Angina <input type="checkbox"/> Acute Coronary Syndrome or Myocardial Infarction <input type="checkbox"/> Percutaneous Intervention <input type="checkbox"/> CABG <input type="checkbox"/> Other		

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<b>Family History of Stroke?</b>	<b>Type of Stroke?</b>	<b>Relationship to participant</b>	
<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Uncertain	<input type="checkbox"/> Ischaemic <input type="checkbox"/> Haemorrhagic <input type="checkbox"/> Not Known		
<b>Family History of ITP?</b>		<b>Relationship to participant</b>	
<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Uncertain			
<b>Family History of Autoimmune Disease?</b>	<b>Autoimmune Disease</b>	<b>Relationship to participant</b>	
<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Uncertain			
<b>Any other relevant family history?</b>	<b>Condition</b>	<b>Relationship to participant</b>	
<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Uncertain			
<b>Biochemical Fields at Diagnosis-</b> Please give these values from time of diagnosis or as close to diagnosis as possible			
<b>Blood Test</b>	<b>Result</b>	<b>Date of Test</b>	
Alanine Transaminase (ALT) (U/L)			
Aspartate Transaminase (AST) (U/L):			
Alkaline Phosphatase (ALP) (U/L):			
Total Bilirubin Level ( $\mu\text{mol/L}$ ):			
<b>Haematological Fields at Diagnosis-</b> Please give these value from time of diagnosis or as close to diagnosis as possible			
<b>Blood Test</b>	<b>Result</b>	<b>Date of Test</b>	
Neutrophil Count ( $\times 10^9/\text{L}$ ):			
White Blood Cells ( $\times 10^9/\text{L}$ ):			
Red Blood Cells ( $\times 10^9/\text{L}$ ):			
Mean Platelet Volume (MPV):			
<b>Blood Group:</b> <input type="checkbox"/> O <input type="checkbox"/> AB <input type="checkbox"/> A <input type="checkbox"/> B <input type="checkbox"/> Unknown			
<b>Platelet Counts-</b> Please use appendix 1 to guide when we need platelet counts. If you have lots of platelet counts you can use our template excel sheet to upload counts. It can be found under File Repository on REDCap. Alternatively email us on <a href="mailto:uk-ity.registryteam@nhs.net">uk-ity.registryteam@nhs.net</a> for a template.			
<b>Platelet Count</b>	<b>Date of Count</b>	<b>Platelet Count</b>	<b>Date of Count</b>



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<b>Activated Partial Thromboplastin Time (APTT)</b>		
<b>Reticulocyte Percentage</b>		
<b>Lupus Anticoagulant (LA)</b>		
<b>Anticardiolipin Antibody- IgG</b>		
<b>Anticardiolipin Antibody- IgM</b>		
<b>Bone Marrow Biopsy and DAT test results</b>		
<b>Did they have this test?</b>	<b>Conclusion</b>	<b>Date of Test</b>
<b>Bone Marrow Aspirate</b> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Uncertain	<input type="checkbox"/> Result consistent with ITP <input type="checkbox"/> Results inconsistent with ITP <input type="checkbox"/> Results inconclusive <input type="checkbox"/> Test not done <input type="checkbox"/> Information not available	
<b>Trephine Biopsy</b> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Uncertain	<input type="checkbox"/> Result consistent with ITP <input type="checkbox"/> Results inconsistent with ITP <input type="checkbox"/> Results inconclusive <input type="checkbox"/> Test not done <input type="checkbox"/> Information not available	
<b>Direct Agglutination Test (DAT)</b>	<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Not tested <input type="checkbox"/> NA	
<b>Indium Scanning</b> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Uncertain	<input type="checkbox"/> Pure Splenic Sequestrations <input type="checkbox"/> Predominant Splenic Sequestrations <input type="checkbox"/> Mixed sequestrations <input type="checkbox"/> Hepatic Sequestrations <input type="checkbox"/> Inconclusive results <input type="checkbox"/> Not stated	