

UK ITP REGISTRY INITIAL INFORMATION SHEET (2.5)



Participant Name:

Date of Data Collection:

Registry Identification Code (RIC):

Participant Details		
Date of Birth:		Gender: <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Uncertain
Ethnicity: White <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 Mixed/Multiple ethnic groups <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		Asian/Asian British <input type="checkbox"/> Indian <input type="checkbox"/> Pakistani <input type="checkbox"/> Bangladeshi <input type="checkbox"/> Chinese <input type="checkbox"/> Any other Asian background Black/ African/Caribbean/Black British <input type="checkbox"/> African <input type="checkbox"/> Caribbean <input type="checkbox"/> Any other Black/African/Caribbean background Other ethnic group <input type="checkbox"/> Arab <input type="checkbox"/> Any other ethnic group
Consent Date:		Date of last ITP-related clinic:
Clinical Information		
Haematologist's name:		Haematologist's hospital:
Was this participant diagnosed with ITP at your centre? <input type="checkbox"/> Yes <input type="checkbox"/> No		
Was this participant referred to your centre for ITP care? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Information not available		
If yes to above:		
Name of referrer:	Speciality of referrer:	Name of GP Practice or Hospital of referrer:
Lifestyle Information- 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.		
Weight (kg):	kg	Height (cm): cm

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Date:	Date:	
Smoking status: <ul style="list-style-type: none"> <input type="checkbox"/> No data available <input type="checkbox"/> Never smoked <input type="checkbox"/> Ex-smoker <input type="checkbox"/> Current smoker 	If ex or current smoker, daily consumption: <ul style="list-style-type: none"> <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 	
Date:		
Does the participant chew tobacco products? <ul style="list-style-type: none"> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No information available 	If yes, which chewing product is used? <ul style="list-style-type: none"> <input type="checkbox"/> Other <input type="checkbox"/> Tobacco <input type="checkbox"/> Betel <input type="checkbox"/> Areca Nut 	
Date:		
Alcohol consumption: <ul style="list-style-type: none"> <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 	Date:	
Bleeding events- Please use headings provided in first row to guide completion of remaining rows		
Type of Bleed	Severity of Bleed	Date of Bleed
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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ITP Treatments			
Surgical treatments			
Has this participant had a splenectomy? <input type="checkbox"/> Yes <input type="checkbox"/> No		If yes, type of splenectomy? <input type="checkbox"/> Laparoscopic <input type="checkbox"/> Open <input type="checkbox"/> Not available	
Medical ITP Treatments- 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 Azathioprine Cyclophosphamide Cyclosporine Danazol Dapsone Dexamethasone Eltrombopag IVIg Methylprednisolone Mycophenolate Prednisolone Rituximab Romiplostin Vinca Alkaloids	g mg/day mg/day mg/week mg/day mg mg/day mg/day g/day mg/day mg/day mg/ day mg/m ² /week µg/kg/week mg/week		

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Blood Product Transfusion			
Blood Product	Dose	No. of consecutive days transfusion given	Date of Transfusion
Red Blood Cells	Units		
Platelets	Units		
Fresh Frozen Plasma	Units		
Cryoprecipitate	Units		
Other ITP-related treatments			
Treatment	Dose	How long was this treatment given for? (days)	Date of Treatment
Protein A Immunoabsorption			
H.pylori Treatment			
Vitamin C Supplements			
Plasmapheresis			
Trial Treatments			
Name of trial	Dose	How long was this treatment given for? (days)	Date of Treatment

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Co-Therapies			
Type of Co-therapy	Name of Treatment	Course	Start Date
Anti-lipid Anti-hypertensive Anti-coagulant Thrombolysis Anti-fibrinolytic		One off Continuous Unknown	Leave blank if still on drug
Co-morbidities			
Co-morbidity		Date of co-morbidity diagnosis	
Family History			
Family History of Cancer?	Site of cancer		Relationship to participant
<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Uncertain			
Family History of Ischaemic Heart Disease?	Type of Ischaemic Heart Disease		Relationship to participant
<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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Family History of Stroke?	Type of Stroke?	Relationship to participant	
<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		
Family History of ITP?		Relationship to participant	
<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Uncertain			
Family History of Autoimmune Disease?	Autoimmune Disease	Relationship to participant	
<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Uncertain			
Any other relevant family history?	Condition	Relationship to participant	
<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Uncertain			
Biochemical Fields at Diagnosis- Please give these values from time of diagnosis or as close to diagnosis as possible			
Blood Test	Result	Date of Test	
Alanine Transaminase (ALT) (U/L)			
Aspartate Transaminase (AST) (U/L):			
Alkaline Phosphatase (ALP) (U/L):			
Total Bilirubin Level (μmol/L):			
Haematological Fields at Diagnosis- Please give these value from time of diagnosis or as close to diagnosis as possible			
Blood Test	Result	Date of Test	
Neutrophil Count (x10⁹/L):			
White Blood Cells (x10⁹/L):			
Red Blood Cells (x10⁹/L):			
Mean Platelet Volume (MPV):			
Blood Group: <input type="checkbox"/> O <input type="checkbox"/> AB <input type="checkbox"/> A <input type="checkbox"/> B <input type="checkbox"/> Unknown			
Platelet Counts- 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 uk-ity.registryteam@nhs.net for a template.			
Platelet Count	Date of Count	Platelet Count	Date of Count

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Immunological Fields- Please give these value from time of diagnosis or as close to diagnosis as possible			
Blood Test	Result	Date of Test	
IgG (mg/dl) Ref range: 639-1349)			
IgM (mg/dl) Ref range: 56-352			
IgA (mg/dl)			
Anti-Nuclear Antibodies <input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Not Tested <input type="checkbox"/> Unknown whether test was done			
Coagulation Fields- Please give these value from time of diagnosis or as close to diagnosis as possible			
Test	Result	Date	
Prothrombin Time (PT)			

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Activated Partial Thromboplastin Time (APTT)		
Reticulocyte Percentage		
Lupus Anticoagulant (LA)		
Anticardiolipin Antibody- IgG		
Anticardiolipin Antibody- IgM		
Bone Marrow Biopsy and DAT test results		
Did they have this test?	Conclusion	Date of Test
Bone Marrow Aspirate <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	
Trephine Biopsy <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	
Direct Agglutination Test (DAT)	<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Not tested <input type="checkbox"/> NA	
Indium Scanning <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	