

UK ITP REGISTRY GENERAL PRACTITIONER DATA COLLECTION SHEET (1.2)



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
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
Date:	Date:
Smoking status: <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: <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? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No information available	If yes, which chewing product is used? <input type="checkbox"/> Other <input type="checkbox"/> Tobacco <input type="checkbox"/> Betel <input type="checkbox"/> Areca Nut
Date:	

UK ITP REGISTRY GENERAL PRACTITIONER DATA COLLECTION SHEET (1.2)

Alcohol consumption: <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

UK ITP REGISTRY GENERAL PRACTITIONER DATA COLLECTION SHEET (1.2)

[illegible]

UK ITP REGISTRY GENERAL PRACTITIONER DATA COLLECTION SHEET (1.2)

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	
Co-Therapies				
Type of Co-therapy	Name of Treatment	Course	Start Date	End date
Anti-lipid		One off		Leave blank if still on drug
Anti-hypertensive		Continuous		
Anti-coagulant		Unknown		
Thrombolysis				
Anti-fibrinolytic				

UK ITP REGISTRY GENERAL PRACTITIONER DATA COLLECTION SHEET (1.2)

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		
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				

UK ITP REGISTRY GENERAL PRACTITIONER DATA COLLECTION SHEET (1.2)

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 ($\mu\text{mol/L}$):			
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 ($\times 10^9/\text{L}$):			
White Blood Cells ($\times 10^9/\text{L}$):			
Red Blood Cells ($\times 10^9/\text{L}$):			
Mean Platelet Volume (MPV):			
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-ityp.registryteam@nhs.net for a template.			
Platelet Count	Date of Count	Platelet Count	Date of Count

UK ITP REGISTRY GENERAL PRACTITIONER DATA COLLECTION SHEET (1.2)

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)		
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	

