

**UK ITP REGISTRY FOLLOW-UP DATA COLLECTION SHEET (1.9)**



**Participant Name:**

**Registry Identification Code:**

Dates of Data Entry		
<b>Date of Follow up:</b>	<b>Are you no longer able to follow-up this participant?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No	
<b>If yes, reason for being unable to follow up participant:</b> <input type="checkbox"/> Discharged <input type="checkbox"/> Moved to different hospital <input type="checkbox"/> Primary ITP diagnosis revised/ changed <input type="checkbox"/> Deceased		
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. Oral Mucosal	Moderate	01/01/2002

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<b>ITP Treatments</b>			
<b>Surgical treatments</b>			
<b>Has this participant had a splenectomy?</b>		<b>If yes, type of splenectomy?</b>	
<input type="checkbox"/> Yes <input type="checkbox"/> No		<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			
<b>Treatment</b>	<b>Dose-</b>	<b>How long was this treatment given for? (days)</b>	<b>Date of Treatment</b>
Anti-D	µg		
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		
<b>Blood Product Transfusion</b>			
<b>Blood Product</b>	<b>Dose</b>	<b>No. of consecutive days transfusion given</b>	<b>Date of Transfusion</b>

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Red Blood Cells	Units			
Platelets	Units			
Fresh Frozen Plasma	Units			
Cryoprecipitate	Units			
<b>Other ITP-related treatments</b>				
<b>Treatment</b>	<b>Dose</b>	<b>How long was this treatment given for? (days)</b>	<b>Date of Treatment</b>	
Protein A Immunoabsorption				
H.pylori Treatment				
Vitamin C Supplements				
Plasmapheresis				
<b>Trial Treatments</b>				
<b>Name of trial</b>	<b>Dose</b>	<b>How long was this treatment given for? (days)</b>	<b>Date of Treatment</b>	
<b>Co-Therapies</b>				
<b>Type of Co-therapy</b>	<b>Name of Treatment</b>	<b>Course</b>	<b>Start Date</b>	<b>End date</b>
Anti-lipid		One off		Leave blank if still on drug
Anti-hypertensive		Continuous		
Anti-coagulant		Unknown		
Thrombolysis				
Anti-fibrinolytic				
<b>Co-morbidities</b>				
<b>Co-morbidity</b>			<b>Date of Co-morbidity</b>	

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<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	
<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>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-ityp.registryteam@nhs.net">uk-ityp.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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