

UK ITP REGISTRY INITIAL INFORMATION SHEET (3.02-6)



Registry Identification Code (RIC):

**UKITP Registry**  
Barts Health NHS Trust  
The Royal London Hospital  
Pathology and Pharmacy Building  
80 Newark Street  
London E1 2ES  
Tel: +44-(0)-20 324 604737-377-7000, Ext: 64114  
Fax: +44-(0)-203-246-0230  
Email: uk-ity.registryteam@nhs.net

Participant Details	
<b>Date of Birth:</b>	<b>Gender:</b> <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Other <input type="checkbox"/> Uncertain
<b>Ethnicity:</b>	<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  Other, please specify:
<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>ITP Diagnosis Date:</b>	
<b>ITP Type:</b> <input type="checkbox"/> Primary ITP <input type="checkbox"/> ITP after a vaccine  <b>Was the ITP observed within the 3 month period after the vaccine? Type:</b> <input type="checkbox"/> Yes – please enter details in the 'Vaccination History' Form. <input type="checkbox"/> No – patient not eligible.	
<b>Consent date for UKITP registry:</b>	
<b>Date of First Data Collection:</b>	
Blood Samples	

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Page 1 of 22

Proforma v3.02-6 – 7<sup>th</sup> September 2014 – 28<sup>th</sup> July 2021  
 Protocol v2.4.4.0 – 4<sup>th</sup> September 2014 – 28<sup>th</sup> July 2021  
 IRAS ID: 92703

UK ITP REGISTRY INITIAL INFORMATION SHEET (3.02-6)

<b>Has the participant consented to provide biological samples?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No	
<b>Was a biological sample sent?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No	
<b>Sample Sent Date:</b>	
<b>Sample Received Date (Registry Team To Complete):</b>	
<b>Clinical Information</b>	
<b>Consultant Haematologist's Initials:</b>	<b>Haematologist's Hospital/Centre Name:</b>
<b>Was the participant diagnosed with ITP at this centre?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No	
<b>Anthropometric and Lifestyle Data</b> - Please enter the following anthropometric and lifestyle information. Please complete at the time of registration. Repeat entries not required.	
<b>Weight (kg):</b> <b>kg</b>	<b>Height (cm):</b> <b>cm</b>
<b>Month of weight:</b>	<b>Month of height:</b>
<b>Year of weight:</b>	<b>Year of height:</b>
<b>Smoking status at consent:</b> <input type="checkbox"/> No data <input type="checkbox"/> Never smoked <input type="checkbox"/> Ex-smoker <input type="checkbox"/> Current smoker	
<b>Month smoking status was record:</b>	
<b>Year smoking status was record:</b>	
<b>Does the participant drink alcohol?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No information available	
<b>Alcohol amount:</b> <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"/> Amount not available	
<b>Month drinking status was recorded:</b>	

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UK ITP REGISTRY INITIAL INFORMATION SHEET (3.02-6)

Year drinking status was recorded:

**Bleeding events-** Please use headings provided in first row to guide completion of remaining rows

Skin		
Bleed Type/Site	Severity of Bleed	Date of Bleed
Bruise Petechiae Subcutaneous Haematoma Bleed from minor wounds Other (please specify)	Bruise severity (number of bruises):  1-5 >5 Unknown	
	Petechiae severity (number of petechiae):  ≤10 >10 >50 Unknown	
	Subcutaneous Haematoma severity:  ≤2 >2 Unknown	
	Minor wound severity:  ≤ 5 mins > 5 mins Unknown	
e.g. Bruise	e.g. >5	e.g. 01/09/2018

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**Mucosal**

Bleed Type/Site	Severity of Bleed based on bleed type/site	Date of Bleed	If Epistaxis bleed, was a transfusion required?
Epistaxis Oral cavity Subjunctional Bleeds Other (please specify)	<p>Epistaxis Severity:</p> <p>Whilst blowing nose</p> <p>Spontaneous and lasting &lt; 5 mins</p> <p>Spontaneous and lasting &gt;5 mins</p> <p>Required packing/cauterisation</p> <p>Unknown</p> <hr/> <p>Oral cavity bleed severity:</p> <p>Gum Bleeding</p> <p>Bullae or blisters</p> <p>Bleeding from bites to lips and tongue</p> <p>Unknown</p>		Yes No
e.g. Oral Cavity	e.g. Bleeding from bites to lips and tongue	e.g. 01/09/2018	

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## UK ITP REGISTRY INITIAL INFORMATION SHEET (3.02-6)


<b>Organ</b>			
<b>Bleed Site (Select one)</b>	<b>Bleed Type (Select based on bleed site)</b>	<b>Was transfusion required</b>	<b>Date of Bleed</b>
Gastrointestinal bleed (e.g. rectal bleed, haematemesis and malaena) Gynaecological bleed Haemarthrosis Intracranial bleed Intramuscular haematoma Ocular haemorrhage Pulmonary haemorrhage (e.g. haemoptysis, bleed into the lungs) Urinary (haematuria) Other internal bleed (please specify)	GI Bleed type:  Occult blood Lower GI bleed Haematemesis and/ or malaena Other (please specify)	Yes No	
	Gynaecological Bleed Type:  Occult blood Lower GI bleed Haematemesis and/ or malaena Other (please specify)		
	Intracranial Bleed Type:  Traumatic Non-traumatic		
	Ocular Bleed		



UK ITP REGISTRY INITIAL INFORMATION SHEET (3.02-6)


Splenectomy

Has this participant had a Splenectomy?

- ☐ Yes  
☐ No

Splenectomy Type:

- ☐ Laparoscopic  
☐ Open  
☐ Not recorded

Splenectomy Date:

ITP Treatments						
Medical ITP Treatments - Please use headings provided in first row to guide completion of remaining rows						
Treatment	Unit of Dose	Dose	Start Date	Is participant still taking this medication ?	If No, end date	How long (days) were steroids prescribed for?

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# UK ITP REGISTRY INITIAL INFORMATION SHEET (3.02-6)

Prednisolone	g					
IVIg	g/day					
Dexamethasone	g/kg/day					
Methylprednisolone	mg					
Mycophenolate	mg/day					
Rituximab	mg/day					
Romiplostim	mg/day					
Eltrombopag	g/day					
Azathioprine	mg/day					
Cyclophosphamide	mg/day					
Cyclosporine	mg/day					
Danazol	mg/m <sup>2</sup> /week					
Dapsone	mg/alternate days					
Vinca Alkaloids	µg/kg/week					
Anti-D	mg/week					
Fostamatinib	Oral					
Avatrombopag	IV					
Other (please specify)	mg OD (once daily)					
	mg BD (twice daily)					
	mg once per week					
	mg twice per week					
	mg three times per week					
	Other					


Page 8 of 22

Proforma v3.02-6 – 7<sup>th</sup> September 2014  
 Protocol v2.4.4.0 – 12<sup>th</sup> July 2021  
 IRAS ID: 92703

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UK ITP REGISTRY INITIAL INFORMATION SHEET (3.02-6)


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Co-morbidities - Please use headings provided in first row to guide completion of remaining rows						
Co-morbidity	Type of Autoimmune disease	Type of Endocrine disorder	Type of Infection	Type of Arterial Thrombosis	Type of Venous Thrombosis	Date of Diagnosis
<ul style="list-style-type: none"> <li>Autoimmune Disease</li> <li>Cataracts</li> <li>Chronic Liver Disease</li> <li>Depression/ Anxiety</li> <li>Endocrine Disorder</li> <li>Hyperlipidaemia/ Hypercholesteraemia</li> <li>Hypertension</li> <li>Infection</li> <li>Renal Failure/Impairment</li> <li>Splenomegaly</li> <li>Thrombosis- Arterial</li> <li>Haemorrhagic Cerebrovascular Accident (Stroke)</li> <li>Thrombosis- Venous</li> <li>Other Bone or Joint Conditions</li> <li>Other Musculoskeletal Conditions</li> <li>Other (please specify)</li> </ul>	<ul style="list-style-type: none"> <li>Antiphospholipid syndrome (APS)</li> <li>Aplastic anemia</li> <li>Autoimmune hepatitis</li> <li>Crohn's disease</li> <li>Evans syndrome</li> <li>Haemolytic anaemia</li> <li>Pernicious Anaemia</li> <li>Rheumatoid arthritis</li> <li>Systemic lupus erythematosus (SLE)</li> <li>Ulcerative colitis</li> <li>Other (please specify)</li> </ul>	<ul style="list-style-type: none"> <li>Diabetes, Type 1</li> <li>Diabetes, Type 2</li> <li>Hyperthyroidism (HYPER-thyroidism)</li> <li>Hypothyroidism (HYPO-thyroidism)</li> <li>Cushing's Syndrome</li> <li>Addison's Disease</li> <li>Other (please specify)</li> </ul>	<ul style="list-style-type: none"> <li>COVID-19</li> <li>Candida Infection</li> <li>Cytomegalovirus</li> <li>H. Pylori Infection</li> <li>Hepatitis A</li> <li>Hepatitis B</li> <li>Hepatitis C</li> <li>Human Immunodeficiency Virus (HIV)</li> <li>Influenza</li> <li>Measles</li> <li>Mumps</li> <li>Other Respiratory Infection (e.g. Upper Airway)</li> <li>Respiratory Infection)</li> <li>Pneumonia (inc. bacterial, viral, fungal or protozoan)</li> <li>Rubella</li> <li>Other (please specify)</li> </ul>	<ul style="list-style-type: none"> <li>Acute Coronary Syndrome/ Myocardial Infarction</li> <li>(ACS)</li> <li>Ischaemic Cerebrovascular Accident (Stroke)</li> <li>Non-cerebral, non-coronary arterial thrombosis</li> <li>(i.e.excludes ACS)</li> <li>Revascularisation Procedure (CABG or PCTA)</li> <li>Stable Angina (SA)</li> <li>Transient Ischaemic Attack (TIA)</li> <li>Other (please specify)</li> </ul>	<ul style="list-style-type: none"> <li>Deep Vein Thrombosis (DVT)</li> <li>Pulmonary Embolism (PE)</li> <li>Portal Vein Thrombosis (PVT)</li> <li>Renal Vein Thrombosis (RVT)</li> <li>Splenic Vein Thrombosis (SpVT)</li> <li>Superficial Vein Thrombosis</li> <li>Other</li> </ul>	

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UK ITP REGISTRY INITIAL INFORMATION SHEET (3.02-6)

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Cancer			
Has the participant ever had a malignancy?	If Haematological Malignancy, type	If Solid Tumour, type	Date of diagnosis
<ul style="list-style-type: none"> <li>Haematological Malignancy</li> <li>Solid Tumour</li> </ul>	<ul style="list-style-type: none"> <li>Acute lymphoblastic leukaemia</li> <li>Acute myeloid leukaemia</li> <li>Chronic lymphocytic leukaemia</li> <li>Chronic myeloid leukaemia</li> <li>Chronic myeloproliferative disease</li> <li>Hodgkins lymphoma</li> <li>Multiple myeloma and malignant plasma cell neoplasms</li> <li>Myelodysplastic syndromes</li> <li>Non- Hodgkins lymphoma</li> <li>Waldenstrom's macroglobulinaemia</li> <li>Other (please specify)</li> </ul>	Malignant neoplasm of adrenal gland Malignant neoplasm of anus and anal canal Malignant neoplasm of bladder Malignant neoplasm of bone and articular cartilage of limbs Malignant neoplasm of brain Malignant neoplasm of breast Malignant neoplasm of bronchus and lung Malignant neoplasm of oral cavity or tonsil Malignant neoplasm of cervix uteri Malignant neoplasm of colon Malignant neoplasm of gallbladder Malignant neoplasm of kidney Malignant neoplasm of larynx Malignant neoplasm of liver Malignant neoplasm of oesophagus Malignant neoplasm of ovary Malignant neoplasm of pancreas Malignant neoplasm of prostate Malignant neoplasm of rectum Malignant melanoma of skin Malignant neoplasm of skin- not melanoma Malignant neoplasm of small intestine Malignant neoplasm of stomach Malignant neoplasm of testis Malignant neoplasm of thyroid gland Malignant neoplasm of trachea Malignant neoplasm of uterus	

UK ITP REGISTRY INITIAL INFORMATION SHEET (3.02-6)

		Malignant neoplasm of vulva Mesothelioma Malignant neoplasm- no specification of site Other (please specify)	

**Family History** - Please use headings provided in first row to guide completion of remaining rows

Family History Disease Type	Type of Autoimmune disease	Type of Cancer	Type of Coagulation Disorder	Type of Ischaemic Heart Disease	Type of Stroke	Relationship to participant
<ul style="list-style-type: none"> <li>• Autoimmune Disease</li> <li>• Cancer</li> <li>• Coagulation Disorder</li> <li>• Immune Thrombocytopenia (ITP)</li> <li>• Ischaemic Heart Disease</li> <li>• Stroke</li> </ul>	<ul style="list-style-type: none"> <li>• Antiphospholipid syndrome (APS)</li> <li>• Aplastic anemia</li> <li>• Autoimmune hepatitis</li> <li>• Crohn's disease</li> <li>• Evans syndrome</li> <li>• Haemolytic anaemia</li> <li>• Pernicious Anaemia</li> <li>• Rheumatoid arthritis</li> <li>• Systemic lupus erythematosus</li> </ul>	Haematological Malignancy <ul style="list-style-type: none"> <li>• Acute lymphoblastic leukaemia</li> <li>• Acute myeloid leukaemia</li> <li>• Chronic lymphocytic leukaemia</li> <li>• Chronic myeloid leukaemia</li> <li>• Chronic myeloproliferative disease</li> <li>• Hodgkins lymphoma</li> <li>• Multiple myeloma and malignant plasma cell neoplasms</li> <li>• Myelodysplastic syndromes</li> <li>• Non- Hodgkins lymphoma</li> <li>• Waldenstrom's macroglobulinaemia</li> <li>• Other (please specify)</li> </ul>	<ul style="list-style-type: none"> <li>• Deep Vein Thrombosis (DVT)</li> <li>• Pulmonary Embolism (PE)</li> <li>• Other (please specify)</li> </ul>	<ul style="list-style-type: none"> <li>• Acute Coronary Syndrome (ACS)</li> <li>• Stable Angina (SA)</li> <li>• Revascularisation Procedure (CABG or PCTA)</li> </ul>	<ul style="list-style-type: none"> <li>• Ischaemic</li> <li>• Haemorrhagic</li> <li>• Not Known</li> </ul>	<ul style="list-style-type: none"> <li>• Mother</li> <li>• Father</li> <li>• Sister</li> <li>• Brother</li> <li>• Identical Twin</li> <li>• Maternal Grandmother</li> <li>• Paternal Grandmother</li> <li>• Grandmother (Side unknown)</li> <li>• Maternal Grandfather</li> <li>• Paternal Grandfather</li> </ul>

# UK ITP REGISTRY INITIAL INFORMATION SHEET (3.02-6)

	(SLE) • Ulcerative colitis • Other (please specify)	Solid Tumour	• Malignant neoplasm of adrenal gland • Malignant neoplasm of anus and anal canal • Malignant neoplasm of bladder • Malignant neoplasm of bone and articular cartilage • of limbs • Malignant neoplasm of brain • Malignant neoplasm of breast • Malignant neoplasm of bronchus and lung • Malignant neoplasm of oral cavity or tonsil • Malignant neoplasm of cervix uteri • Malignant neoplasm of colon • Malignant neoplasm of gallbladder • Malignant neoplasm of kidney • Malignant neoplasm of larynx • Malignant neoplasm of liver • Malignant neoplasm of oesophagus • Malignant neoplasm of ovary • Malignant neoplasm of pancreas • Malignant neoplasm of prostate • Malignant neoplasm of rectum • Malignant melanoma of skin • Malignant neoplasm of skin- not melanoma • Malignant neoplasm of small intestine • Malignant neoplasm of stomach • Malignant neoplasm of testis • Malignant neoplasm of thyroid				• Grandfather (Side unknown)
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UK ITP REGISTRY INITIAL INFORMATION SHEET (3.02-6)

			<div>gland</div> <ul style="list-style-type: none"><li>• Malignant neoplasm of trachea</li><li>• Malignant neoplasm of uterus</li><li>• Malignant neoplasm of vulva</li><li>• Mesothelioma</li><li>• Malignant neoplasm- no specification of site</li><li>• Other (please specify)</li></ul>				



## UK ITP REGISTRY INITIAL INFORMATION SHEET (3.02-6)

## Vaccination History

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Page 19 of 22

Proforma v~~3.02-6~~ – ~~7<sup>th</sup> September 2021~~ ~~28<sup>th</sup> July 2021~~ ~~14<sup>th</sup> September 2018~~  
Protocol v~~2.4.4.0~~ – ~~12<sup>th</sup> July 2021~~ ~~28<sup>th</sup> July 2021~~ ~~7<sup>th</sup> September 2018~~  
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**Biochemical Test 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
Haemoglobin (g/l)		
Neutrophil Count (x10 <sup>9</sup> /L):		
White Blood Cells (x10 <sup>9</sup> /L):		
Red Blood Cells (x10 <sup>9</sup> /L):		
Platelet Count ( x10 <sup>9</sup> /L):		
Mean Platelet Volume (fl)		
<b>Blood Group:</b> <input type="checkbox"/> O <input type="checkbox"/> AB <input type="checkbox"/> A <input type="checkbox"/> B <input type="checkbox"/> Unknown/Untested	<b>RhD Status:</b> <input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Untested <input type="checkbox"/> NA	Date:

**Immunological Fields At ITP Diagnosis** - Please give these value from time of diagnosis or as close to diagnosis as possible

Blood Test	Result	Date of Test
<b>IgG</b> (mg/dl) Ref range: 639-1349		
<b>IgM</b> (mg/dl) Ref range: 56-352		
<b>IgA</b> (mg/dl) Ref range: 70-312		
<b>Anti-Nuclear Antibodies</b> <input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Not Tested Unknown whether test was done		

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<b>Bone Marrow Biopsy and DAT test results</b>		
Did they have this test?	Date of Test	Conclusion
<b>Bone Marrow Aspirate</b> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Uncertain		<input type="checkbox"/> Results consistent with ITP <input type="checkbox"/> Results inconsistent with ITP <input type="checkbox"/> Inconclusive Results <input type="checkbox"/> Not Tested <input type="checkbox"/> Not Available <input type="checkbox"/> Other
<b>Trephine Biopsy</b> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Uncertain		<input type="checkbox"/> Free Text <input type="checkbox"/> Results consistent with ITP <input type="checkbox"/> Results inconsistent with ITP <input type="checkbox"/> Inconclusive Results <input type="checkbox"/> Not Tested <input type="checkbox"/> 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  <b>Indium scan:</b>		<input type="checkbox"/> Pure Splenic Sequestrations <input type="checkbox"/> Predominant Splenic Sequestrations <input type="checkbox"/> Mixed Sequestrations <input type="checkbox"/> Hepatic Sequestration <input type="checkbox"/> Inconclusive results <input type="checkbox"/> Not stated