

# UK ITP REGISTRY INITIAL INFORMATION SHEET (5.0)



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"/> Other <input type="checkbox"/> Uncertain
<b>Ethnicity:</b>  <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 <input type="checkbox"/> Unknown  Other, please specify:
<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	
<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>	

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

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

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<b>Skin</b>			
<b>Bleed Type/Site</b>	<b>Severity of Bleed</b>	<b>Date of Bleed</b>	
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	
<b>Mucosal</b>			
<b>Bleed Type/Site</b>	<b>Severity of Bleed based on bleed type/site</b>	<b>Date of Bleed</b>	<b>If Epistaxis bleed, was a transfusion required?</b>

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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)	Occult blood Lower GI bleed Haematemesis and/ or malaena Other (please specify)	No	
	Gynaecological Bleed Type:  Spotting (in between periods) Menorrhagia Post- menopausal bleeding Antepartum bleed Other (please specify)		
	Intracranial Bleed Type:  Traumatic Non-traumatic		
	Ocular Bleed Type:  Retinal bleeds Vitreous bleeds Other (please specify)		
	Haematuria Bleed Type:  Microscopic Macroscopic		
e.g. Ocular haemorrhage	e.g. Vitreous bleeds	e.g. Yes	e.g. 01/09/2018

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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	If No, end date	How long (days) were steroids prescribed for?

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

Supportive Therapies					
Treatment	No. of Units (if applicable)	If Tranexamic acid, how was this given?	Start Date	End date	
Red Blood Cell Transfusion		One off			

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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 (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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COVID-19							
What was the maximum level of care required for the patient due to the COVID-19 diagnosis?	Did the patient bleed?	Did the patients platelet count drop?	Did the patient require treatment for COVID-19?	If 'Yes', Name of treatment received for COVID-19 (Select all that apply)	If 'No', Why was the decision taken not to treat?	Did the patient take part in any COVID-19 clinical trial? If 'Yes', please give name of trial.	Is the patient alive?
<ul style="list-style-type: none"> <li>• Outpatient management</li> <li>• Inpatient stay no oxygen</li> <li>• One of: oxygen through CPAP / hi-flow OR cardiovascular support OR renal replacement therapy</li> <li>• Two of: oxygen through CPAP / hi-flow OR cardiovascular support OR renal replacement therapy</li> <li>• Intubation and ventilation</li> <li>• ECMO</li> </ul>	<ul style="list-style-type: none"> <li>• Yes (please enter details in the 'Bleeding events' form)</li> <li>• No</li> <li>• Uncertain</li> </ul>	<ul style="list-style-type: none"> <li>• Yes (please enter platelet count information in the 'Full Blood Counts (Hbs, Neutrophils, Plts)' form)</li> <li>• No</li> <li>• Uncertain</li> </ul>	<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Uncertain</li> </ul>	<ul style="list-style-type: none"> <li>• Dexamethasone</li> <li>• Low Molecular Weight Heparin</li> <li>• Tocilizumab</li> <li>• Sarilumab</li> <li>• Remdesivir</li> <li>• Treatment for ITP (please enter details in the 'ITP Treatments form')</li> <li>• Other</li> </ul>	<ul style="list-style-type: none"> <li>• Not indicated on basis of platelet nadir</li> <li>• Treatment indicated, but deemed too high risk because of COVID</li> <li>• Treatment indicated, but deemed too high risk because of non-COVID reasons,</li> <li>• Patient choice</li> <li>• Other</li> </ul>		<ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> <li>• Uncertain</li> </ul>

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

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<b>Family History</b> - 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> <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>	<b>Haematological Malignancy</b> <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>	<b>Solid Tumour</b> <ul style="list-style-type: none"> <li>• Malignant neoplasm of adrenal gland</li> <li>• Malignant neoplasm of anus and anal canal</li> <li>• Malignant neoplasm of bladder</li> <li>• Malignant neoplasm of bone and articular cartilage of limbs</li> <li>• Malignant neoplasm of brain</li> <li>• Malignant neoplasm of breast</li> <li>• Malignant neoplasm of</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> <li>• Other (please specify)</li> <li>• Unknown</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> <li>• Grandfather (Side unknown)</li> <li>• Other (please specify)</li> <li>• Unknown</li> </ul>

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

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Vaccination History								
What vaccine did the patient receive?	If COVID-19 vaccine, which vaccine type did the patient receive?	Date of vaccine	Did the patient receive a second vaccine dose?	Which COVID-19 vaccine type did the patient receive?	Date of second vaccine	Did the patient receive a third/booster dose for the COVID-19 vaccine?	Which COVID-19 vaccine type did the patient receive?	Date of third/booster vaccine

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COVID-19 vaccine Flu vaccine Hepatitis A vaccine Hepatitis B vaccine Haemophilus influenzae type b (Hib) vaccine Pneumococcal vaccine Meningitis B vaccine Hib/Men C vaccine Meningitis ACWY vaccine Other (please specify) Not known	Pfizer-BioNTech Oxford-AstraZeneca Moderna Other (please specify) Not known		Yes No Uncertain	Pfizer-BioNTech Oxford-AstraZeneca Moderna Other (please specify) Not known		Yes No Uncertain	Pfizer-BioNTech Oxford-AstraZeneca Moderna Other (please specify) Not known	

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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 ( $\mu\text{mol/L}$ ):		
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
Haemoglobin (g/l)		
Neutrophil Count ( $\times 10^9/\text{L}$ ):		
White Blood Cells ( $\times 10^9/\text{L}$ ):		
Red Blood Cells ( $\times 10^9/\text{L}$ ):		
Platelet Count ( $\times 10^9/\text{L}$ ):		
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"/> Untested <input type="checkbox"/> NA		



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

**Prothrombin Time (PT):**

**PT Reference Value:**

**PT Ratio (INR)**

**Date:**

**Activated Partial Thromboplastin Time (APTT):**

**APTT Ratio:**

**Date:**

**Other Tests**

Test	Value/Result	Date
<b>Reticulocyte Count</b>		
<b>Reticulocyte Percentage</b>		
<b>Lupus Anticoagulant (LA)</b> <input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Untested <input type="checkbox"/> NA		
<b>Anticardiolipin Antibody- IgG</b> <input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Untested <input type="checkbox"/> NA		
<b>Anticardiolipin Antibody- IgM</b> <input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Untested <input type="checkbox"/> NA		
<b>Anti-Beta-2-Glycoprotein 1 Antibodies (IgG)</b> <input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Untested <input type="checkbox"/> NA		
<b>Anti-Beta-2-Glycoprotein 1 Antibodies (IgM)</b> <input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Untested <input type="checkbox"/> NA		

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