

UK ITP REGISTRY INITIAL INFORMATION SHEET (3.0)



Registry Identification Code (RIC):

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

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Sample Received Date (Registry Team To Complete):	
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): kg	Height (cm): 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:	

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Organ			
Bleed Site (Select one)	Bleed Type (Select based on bleed site)	Was transfusion required	Date of Bleed
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 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 medication ?	If No, end date	How long (days) were steroids prescribed for?
Prednisolone IVIg Dexamethasone Methylprednisolone Mycophenolate Rituximab Romiplostim Eltrombopag Azathioprine Cyclophosphamide Cyclosporine Danazol Dapsone Vincaloids Anti-D Fostamatinib Avatrombopag Other (please specify)	g g/day g/kg/day mg mg/daymg/week mg/m ² /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 Other					

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

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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"> • Outpatient management • Inpatient stay • no oxygen • One of: oxygen through CPAP / hi-flow OR cardiovascular support OR renal replacement therapy • Two of: oxygen through CPAP / hi-flow OR cardiovascular support OR renal replacement therapy • Intubation and ventilation • ECMO 	<ul style="list-style-type: none"> • Yes (please enter details in the 'Bleeding events' form) • No • Uncertain 	<ul style="list-style-type: none"> • Yes (please enter platelet count information in the 'Full Blood Counts (Hbs, Neutrophils, Plts)' form) • No • Uncertain 	<ul style="list-style-type: none"> • Yes • No • Uncertain 	<ul style="list-style-type: none"> • Dexamethasone • Low Molecular Weight Heparin • Tocilizumab • Sarilumab • Remdesivir • Treatment for ITP (please enter details in the 'ITP Treatments form') • Other 	<ul style="list-style-type: none"> • Not indicated on basis of platelet nadir • Treatment indicated, but deemed too high risk because of COVID • Treatment indicated, but deemed too high risk because of non-COVID reasons, • Patient choice • Other 		<ul style="list-style-type: none"> • Yes • No • Uncertain

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

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	(SLE) <ul style="list-style-type: none"> • Ulcerative colitis • Other (please specify) 	Solid Tumour	<ul style="list-style-type: none"> • 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 				<ul style="list-style-type: none"> • Grandfather (Side unknown)
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			<ul style="list-style-type: none"> • 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 require a second vaccine dose?	Which COVID-19 vaccine type did the patient receive?	Date of second vaccine	Did the patient require a third/booster dose for the COVID-19 vaccine?	Which COVID-19 vaccine type did the patient receive?	Date of third/booster vaccine
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)		
Blood Group: <input type="checkbox"/> O <input type="checkbox"/> AB <input type="checkbox"/> A <input type="checkbox"/> B <input type="checkbox"/> Unknown/Untested	RhD Status: <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
IgG (mg/dl) Ref range: 639-1349		
IgM (mg/dl) Ref range: 56-352		
IgA (mg/dl) Ref range: 70-312		
Anti-Nuclear Antibodies <input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Not Tested Unknown whether test was done		
Coagulation Fields At ITP Diagnosis - Please give these value from time of diagnosis or as close to diagnosis as possible		

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Bone Marrow Biopsy and DAT test results		
Did they have this test?	Date of Test	Conclusion
Bone Marrow Aspirate <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
Trephine Biopsy <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
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 Indium scan:		<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