

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)-20324 604737-377-7000, Ext: 64114
 Fax: +44-(0)-203-246-0230
 Email: uk-ity.registryteam@nhs.net

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	

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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:	
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):	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 recorded:	
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:	

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Year drinking status was recorded:

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

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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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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"> <u>COVID-19</u> 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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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	

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		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"> • 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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	<p>(SLE)</p> <ul style="list-style-type: none"> • Ulcerative colitis • Other (please specify) 	<p>Solid Tumour</p>	<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 				<ul style="list-style-type: none"> • Grandfather (Side unknown)
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			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	Formatted Table							
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 (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
Haemaglobin (g/l)		
Neutrophil Count (x10 ⁹ /L):		
White Blood Cells (x10 ⁹ /L):		
Red Blood Cells (x10 ⁹ /L):		
Platelet Count (x10 ⁹ /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		

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