

UK ITP REGISTRY FOLLOW UP INFORMATION SHEET (~~3.02.0~~)



Registry Identification Code:

Dates of Follow Ups	
Date of Follow up data entry:	What is the current status of the participant? <input type="checkbox"/> Active <input type="checkbox"/> Discharged <input type="checkbox"/> Moved to a different hospital <input type="checkbox"/> Lost to follow-up <input type="checkbox"/> Primary ITP diagnosis revised/changed <input type="checkbox"/> Deceased
If moved to a different hospital, please give name of the new Haematologist and Hospital Name, Address and contact details: 	
If Primary ITP diagnosis revised/changed, what is the current diagnosis if it is no longer primary ITP? 	
If deceased:	
Participant Date of Death	
Participant Primary Cause of Death	
Participant Secondary Cause of Death	

UKITP Regis
 Barts Health NHS T
 The Royal London Hosp
 Pathology and Pharmacy Bui
 80 Newark St
 London E1 2
 Tel: +44-(0)-207-377-7000, Ext: 61
 Fax: +44-(0)-203-246-0
 Email: uk-ity.registryteam@nhs

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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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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?
Prednisolone	g					
IVIg	g/day					
Dexamethasone	g/kg/day					
Methylprednisolone	mg					
Mycophenolate	mg/day					
Rituximab	mg/day					
Romiplostim	mg/day					
Eltrombopag	mg/m2/week					
Azathioprine	mg/alternate days					
Cyclophosphamide	g/day					
Cyclosporine	mg/day					
Danazol	mg/day					
Dapsone	mg/day					
Vinca Alkaloids	mg/m2/week					
Anti-D	µg/kg/week					
Fostamatinib	mg OD (once daily)					
Avatrombopag	mg BD (twice daily)					
Other (please specify)	mg once per week					
	mg twice per week					
	mg three times per week					
	mg/week					
	Oral					
	IV					
	Other					

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Supportive Therapies				
Treatment	No. of Units (if applicable)	If Tranexamic acid, how was this given?	Start Date	End date
Red Blood Cell Transfusion Platelet Transfusion Fresh Frozen Plasma Transfusion Cryoprecipitate Transfusion Tranexamic Acid H.Pylori Treatment Plasmapheresis Protein A Immunoadsorption		One off Continuous Unknown		

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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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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	

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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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	(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 				<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								
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	

UK ITP REGISTRY FOLLOW-UP DATA COLLECTION SHEET (~~23.0~~)

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Proforma v~~3.02.0~~ – ~~28th September~~ ~~4th September 2018~~
Protocol v~~4.02.3~~ – ~~28th July~~ ~~7th September 2021~~ ~~16th May 2018~~
IRAS ID: 92703