

UK ITP REGISTRY FOLLOW UP INFORMATION SHEET (2.0)



Registry Identification Code:

Dates of Follow Ups	
Date of Follow up data entry:	What is the current status of the participant? <ul style="list-style-type: none"> <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	

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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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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"> 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 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	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 (SLE) • Ulcerative colitis • Other (please specify) 	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"> • Mother • Father • Sister • Brother • Identical Twin • Maternal Grandmother • Paternal Grandmother • Grandmother (Side unknown) • Maternal Grandfather • Paternal Grandfather • Grandfather (Side unknown)
		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 	

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			<ul style="list-style-type: none"> • 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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UK ITP REGISTRY FOLLOW-UP DATA COLLECTION SHEET (2.0)

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