UK ITP REGISTRY FOLLOW UP INFORMATION SHEET (4.10)

Barts and The London
School of Medicine and Dentistry

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Registry Identification Code:

Dates of Follow Ups	
Date of Follow up data entry:	**What is the current status of the participant?** ☐ Active ☐ Discharged ☐ Moved to a different hospital ☐ Lost to follow-up ☐ Primary ITP diagnosis revised/changed ☐ 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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Bleeding events- Please use headings provided in first row to guide completion of remaining rows		
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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Mucosal			
Bleed Type/Site	**Severity of Bleed based on bleed type/site**	**Date of Bleed**	**If Epistaxis bleed, was a transfusion required?**
Epistaxis Oral cavity Subjunctional Bleeds Other (please specify)	Epistaxis Severity: Whilst blowing nose Spontaneous and lasting < 5 mins Spontaneous and lasting >5 mins Required packing/cauterisation Unknown		Yes No
	Oral cavity bleed severity: Gum Bleeding Bullae or blisters Bleeding from bites to lips and tongue Unknown		
e.g. Oral Cavity	e.g. Bleeding from bites to lips and tongue	e.g. 01/09/2018	

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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: Spotting (in between periods) Menorrhagia Post-menopausal bleeding Antepartum bleed ~~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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Other

Bleed Type	Date of Bleed
Post-procedural bleed Other (please specify)	
e.g. Post-procedural bleed	01/09/2018

Splenectomy

Has this participant had a Splenectomy?

- ☐ Yes
- ☐ No

Splenectomy Type:

- ☐ Laparoscopic
- ☐ Open

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☐ 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 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/m2/week mg/alternate days µg/kg/week mg OD (once daily) mg BD (twice daily) mg once per week mg twice per week mg three times per 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**
• 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)	• Antiphospholipid syndrome (APS) • Aplastic anaemia • Autoimmune hepatitis • Crohn's disease • Evans syndrome • Haemolytic anaemia • Pernicious Anaemia • Rheumatoid arthritis • Systemic lupus erythematosus (SLE) • Ulcerative colitis • Other (please specify)	• Diabetes, Type 1 • Diabetes, Type 2 • Hyperthyroidism (HYPER-thyroidism) • Hypothyroidism (HYPO-thyroidism) • Cushing's Syndrome • Addison's Disease • Other (please specify)	• 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)	• 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)	• 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?**
• 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	• Yes (please enter details in the 'Bleeding events' form) • No • Uncertain	• Yes (please enter platelet count information in the 'Full Blood Counts (Hbs, Neutrophils, Plts)' form) • No • Uncertain	• Yes • No • Uncertain	• Dexamethasone • Low Molecular Weight Heparin • Tocilizumab • Sarilumab • Remdesivir • Treatment for ITP (please enter details in the 'ITP Treatments form') • Other	• 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		• 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**
• Haematological Malignancy • Solid Tumour	• 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
• Autoimmune Disease • Cancer • Coagulation Disorder • Immune Thrombocytopenia (ITP) • Ischaemic Heart Disease • Stroke • Other (please specify)	• Antiphospholipid syndrome (APS) • Aplastic anaemia • Autoimmune hepatitis • Crohn's disease • Evans syndrome • Haemolytic anaemia • Pernicious Anaemia • Rheumatoid arthritis • Systemic lupus erythematosus	Haematological Malignancy	• 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)	• Deep Vein Thrombosis (DVT) • Pulmonary Embolism (PE) • Other (please specify)	• Acute Coronary Syndrome (ACS) • Stable Angina (SA) • Revascularisation Procedure (CABG or PCTA) • Other (please specify) • Unknown	• Ischaemic • Haemorrhagic • Not Known	• Mother • Father • Sister • Brother • Identical Twin • Maternal Grandmother • Paternal Grandmother • Grandmother (Side unknown) • Maternal Grandfather • Paternal Grandfather

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	(SLE) • Ulcerative colitis • Other (please specify)	Solid Tumour	• 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				• Grandfather (Side unknown) • Other (please specify) • Unknown

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			• 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**
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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Full Blood Counts (Hbs, Neutrophils, Plts)		
Test	**Value**	**Date**
Haemoglobin (g/ l) Neutrophils (x10^9 /L) Platelet Count		

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