

UK ITP REGISTRY GENERAL PRACTITIONER DATA COLLECTION SHEET (1.2)



Participant Name:

Date of Data Collection:

Registry Identification Code (RIC):

| Participant Details | |
|---|---|
| Date of Birth: | Gender: <input type="checkbox"/> Male <input type="checkbox"/> Female <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 |
| Lifestyle Information- questions in this section should be answered with values from time of diagnosis if possible. If answers aren't available at diagnosis, please give the measurements as close to diagnosis as possible. | |
| Weight (kg): kg | Height (cm): cm |
| Date: | Date: |
| Smoking status: <input type="checkbox"/> No data available <input type="checkbox"/> Never smoked <input type="checkbox"/> Ex-smoker <input type="checkbox"/> Current smoker | If ex or current smoker, daily consumption: <input type="checkbox"/> Occasional <input type="checkbox"/> <10 a day <input type="checkbox"/> 11-20 a day <input type="checkbox"/> 21-40 a day <input type="checkbox"/> >40 a day |
| Date: | |
| Does the participant chew tobacco products? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No information available | If yes, which chewing product is used? <input type="checkbox"/> Other <input type="checkbox"/> Tobacco <input type="checkbox"/> Betel <input type="checkbox"/> Areca Nut |
| Date: | |

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|--|---|----------------------|
| Alcohol consumption: <input type="checkbox"/> None <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"/> Consumption not available | | Date: |
| Bleeding events- Please use headings provided in first row to guide completion of remaining rows | | |
| Type of Bleed | Severity of Bleed | Date of Bleed |
| Bruise Cutaneous Bleeds Epistaxis Gastrointestinal bleeding Haematemesis Haematuria Haemoptysis Intracranial Haemorrhage (non-traumatic) Intracranial Haemorrhage (traumatic) Joint Bleeds Menorrhagia Muscle Bleeds Oral mucosal Other intra-ocular bleed Pulmonary haemorrhage Retinal Bleeds Subconjunctival Bleeds Uterine Bleeds Vitreous haemorrhage Other (Please Specify) | Mild- minor bruising/ bleeding and/or petechia that was resolved quickly and spontaneously. Moderate- prolonged bleeding (e.g. epistaxis, extensive bruising, wet purpura) that did not require intervention. Severe- e.g. requiring haemostatic intervention, transfusion, any intracranial haemorrhage or haemodynamic instability. | |
| e.g. Epistaxis | Moderate | 01/01/2012 |
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UK ITP REGISTRY GENERAL PRACTITIONER DATA COLLECTION SHEET (1.2)

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| Blood Product Transfusion | | | | |
|------------------------------|-------------------|---|---------------------|------------------------------|
| Blood Product | Dose | No. of consecutive days transfusion given | Date of Transfusion | |
| Red Blood Cells | Units | | | |
| Platelets | Units | | | |
| Fresh Frozen Plasma | Units | | | |
| Cryoprecipitate | Units | | | |
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| Other ITP-related treatments | | | | |
| Treatment | Dose | How long was this treatment given for? (days) | Date of Treatment | |
| Protein A Immunoabsorption | | | | |
| H.pylori Treatment | | | | |
| Vitamin C Supplements | | | | |
| Plasmapheresis | | | | |
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| Trial Treatments | | | | |
| Name of trial | Dose | How long was this treatment given for? (days) | Date of Treatment | |
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| Co-Therapies | | | | |
| Type of Co-therapy | Name of Treatment | Course | Start Date | End date |
| Anti-lipid | | One off | | Leave blank if still on drug |
| Anti-hypertensive | | Continuous | | |
| Anti-coagulant | | Unknown | | |
| Thrombolysis | | | | |
| Anti-fibrinolytic | | | | |
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| Co-morbidities | | | | |
| Co-morbidity | | Date of co-morbidity diagnosis | | |
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| Family History | | | | |
| Family History of Cancer? | | Site of cancer | Relationship to participant | |
| <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Uncertain | | | | |
| Family History of Ischaemic Heart Disease? | | Type of Ischaemic Heart Disease | Relationship to participant | |
| <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Uncertain | | <input type="checkbox"/> Stable Angina <input type="checkbox"/> Acute Coronary Syndrome or Myocardial Infarction <input type="checkbox"/> Percutaneous Intervention <input type="checkbox"/> CABG <input type="checkbox"/> Other | | |
| Family History of Stroke? | | Type of Stroke? | Relationship to participant | |
| <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Uncertain | | <input type="checkbox"/> Ischaemic <input type="checkbox"/> Haemorrhagic <input type="checkbox"/> Not Known | | |
| Family History of ITP? | | Relationship to participant | | |
| <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Uncertain | | | | |
| Family History of Autoimmune Disease? | | Autoimmune Disease | Relationship to participant | |
| <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Uncertain | | | | |

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| Any other relevant family history? | Condition | Relationship to participant | |
| <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Uncertain | | | |
| Biochemical Fields 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 | |
| Neutrophil Count (x10⁹/L): | | | |
| White Blood Cells (x10⁹/L): | | | |
| Red Blood Cells (x10⁹/L): | | | |
| Mean Platelet Volume (MPV): | | | |
| Blood Group: <input type="checkbox"/> O <input type="checkbox"/> AB <input type="checkbox"/> A <input type="checkbox"/> B <input type="checkbox"/> Unknown | | | |
| Platelet Counts- Please use appendix 1 to guide when we need platelet counts. If you have lots of platelet counts you can use our template excel sheet to upload counts. It can be found under File Repository on REDCap. Alternatively email us on uk-itp.registryteam@nhs.net for a template. | | | |
| Platelet Count | Date of Count | Platelet Count | Date of Count |
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| Immunological Fields- 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) | | |
| Anti-Nuclear Antibodies <input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Not Tested <input type="checkbox"/> Unknown whether test was done | | |
| Coagulation Fields- Please give these value from time of diagnosis or as close to diagnosis as possible | | |
| Test | Result | Date |
| Prothrombin Time (PT) | | |
| Activated Partial Thromboplastin Time (APTT) | | |
| Reticulocyte Percentage | | |
| Lupus Anticoagulant (LA) | | |
| Anticardiolipin Antibody- IgG | | |
| Anticardiolipin Antibody- IgM | | |
| Bone Marrow Biopsy and DAT test results | | |
| Did they have this test? | Conclusion | Date of Test |
| Bone Marrow Aspirate <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Uncertain | <input type="checkbox"/> Result consistent with ITP <input type="checkbox"/> Results inconsistent with ITP <input type="checkbox"/> Results inconclusive <input type="checkbox"/> Test not done <input type="checkbox"/> Information not available | |
| Trephine Biopsy <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Uncertain | <input type="checkbox"/> Result consistent with ITP <input type="checkbox"/> Results inconsistent with ITP <input type="checkbox"/> Results inconclusive <input type="checkbox"/> Test not done <input type="checkbox"/> Information 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 | <input type="checkbox"/> Pure Splenic Sequestrations <input type="checkbox"/> Predominant Splenic Sequestrations <input type="checkbox"/> Mixed sequestrations <input type="checkbox"/> Hepatic Sequestrations <input type="checkbox"/> Inconclusive results <input type="checkbox"/> Not stated | |

