

UK ADULT ITP REGISTRY NEWSLETTER



Issue 011

JUL 2024

WELCOME

Hello and welcome to the latest edition of our UK Adult ITP Registry Study Newsletter. Thank you to all sites and research staff for their ongoing support and hard work.

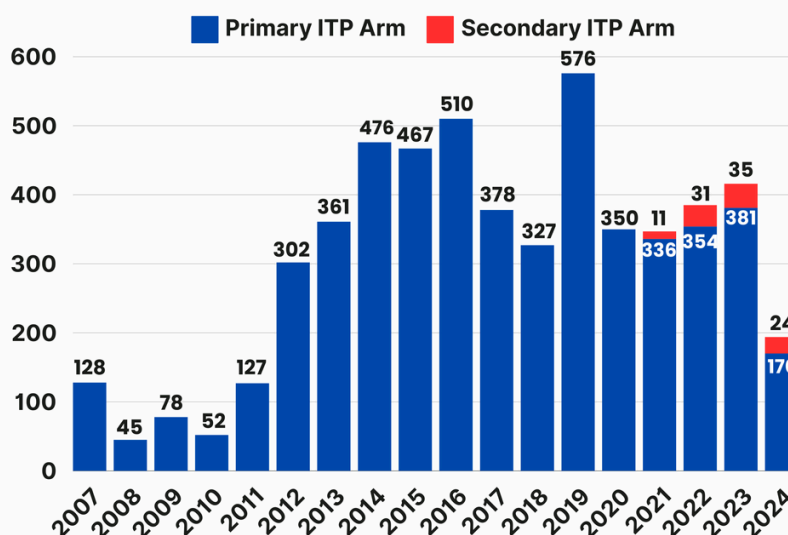
In our last newsletter, we confirmed that the Secondary ITP arm of the registry went live on REDCap; we've had a great response from sites and recruitment is going well so far.

RECRUITMENT

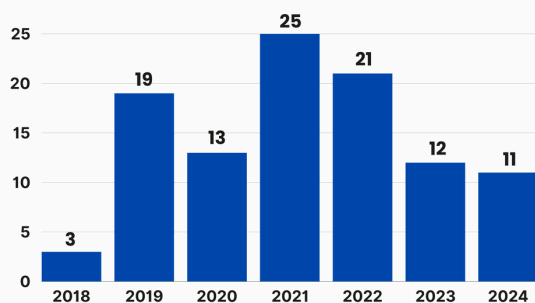
As of 25 July 2024, there are 5,521 participants recruited in the UK Adult ITP Registry Study:

- 5,420 participants in the main Primary ITP arm (of which, 101 participants are also in the pregnancy ITP arm).
- 101 participants in the Secondary ITP arm (of which, 3 participants are also in the pregnancy ITP arm).

UK ADULT ITP REGISTRY CUMULATIVE RECRUITMENT



PREGNANCY REGISTRY RECRUITMENT



We have now recruited 104 participants into the pregnancy arm! A massive thank you to all sites for their hard work. Please review patients' delivery dates and ensure their REDCap record is up to date. If you have any questions, please do not hesitate to reach out to us.

A breakdown of all recruitment numbers by sites and regions can be viewed via our [Tableau dashboard](#).

REDCap database

There are no new updates relating to the REDCap database. However, please continue to enter the data for all patients in a timely manner; baseline data should be entered for new recruits within 6 weeks of consent and follow up should be completed at least once annually. A reminder for all sites to regularly check the 'Resolve Issues' link on REDCap to review which fields/forms have been queried or need completing. When completing queries on REDCap, please ensure that you respond to the query using the dialogue box to confirm that the query has been addressed, selecting the relevant response from the drop down boxes.

UK ADULT ITP REGISTRY NEWSLETTER



Issue 011

JUL 2024

This will then send a notification to the registry team to review the response and close out the query.

If the query isn't responded to like this, we will not be notified of the updated data being added to the field and the query will remain unresolved. If you have any questions regarding this, please contact the registry team.

A screenshot of a web application window titled 'Data Resolution Workflow'. It contains a video link, a description of the workflow, and a table of activity logs. The table has columns for Date/Time, User, and Comments and Details. The first row shows an action 'Opened query' by user 'hmiah' on 25/07/2024 at 8:36am. The second row shows a 'Reply with response' by user 'testuser' at the same time, with a comment 'Data entered now'. Below the table are buttons for 'Respond to query' and 'Cancel'.

Data Resolution Workflow

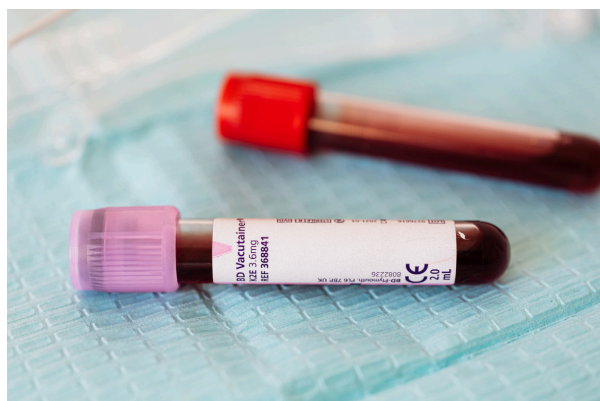
[VIDEO: Data Resolution Workflow](#)

This pop-up displays the Data Resolution Workflow for the specified record for a given field and/or Data Quality rule. Users with appropriate user privileges may open data queries to begin a documented process of resolving an issue with the data. Opened data queries may thus be responded to by users with appropriate privileges, and then they may be closed once the issue has been resolved. All data queries can also be viewed on the Resolve Issues page in this project.

Registry Identification Code (RIC) : **ABC12345**
Event: **UK ITP Registry (Arm 1: UK ITP Registry)**
Field: **dose ("Dose")**
Status: **Open / Unresolved (unresponded)**

Date/Time	User	Comments and Details
25/07/2024 8:36am	hmiah	Action: Opened query Comment: "Question unanswered; please review."
25/07/2024 8:36am	testuser	Reply with response: Other Upload file (optional): Upload document Comment: Data entered now

[Respond to query](#) [Cancel](#)



When samples are being sent to the registry office, please complete the 'specimen transfer form', and enclose it with the samples. Full details can be found on our website via:

<https://www.qmul.ac.uk/itpregistry/study-documents/study-blood-samples/>.

PUBLICATIONS AND PRESENTATIONS

We are pleased to announce the publication of our first paper on Artificial Intelligence (AI) & Machine Learning (ML) and its application in ITP, titled 'Can Machine Learning Assist in Diagnosis of Primary Immune Thrombocytopenia? A Feasibility Study'. This was a joint collaboration with the School of Electronic Engineering & Computer Science, Queen Mary University of London. We look forward to building on this work and further exploring the field of AI/ML and its application in healthcare.

The paper can be downloaded from <https://www.mdpi.com/2075-4418/14/13/1352>.

A full list of publications and presentations can be found on our [website](#).

UK ADULT ITP REGISTRY NEWSLETTER

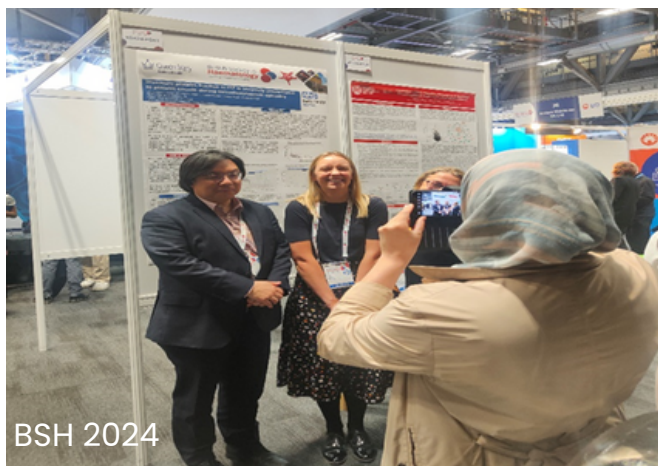
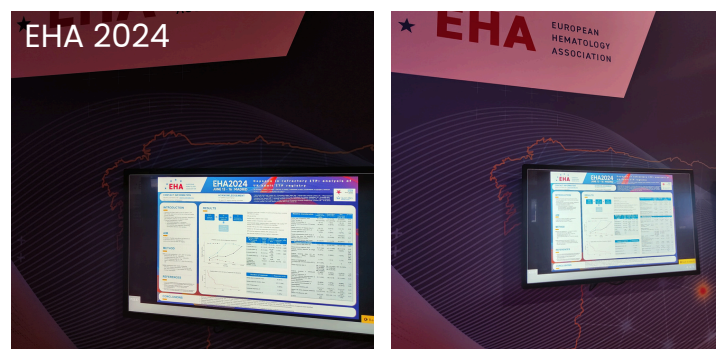


Issue 011

JUL 2024

European Hematology Association (EHA) June 2024 – Poster presentations:

- The outcome of splenectomy in refractory ITP is poor: an analysis of the UKAITP registry.
- Dapsone in refractory ITP: analysis of UK adult ITP registry.
- Use of corticosteroid-sparing treatments (second line and beyond) in adult patients with primary immune thrombocytopenia in Europe. A parallel study in six prospective multicenter national registries.



BSH 2024

British Society for Haematology (BSH) April 2024:

- Poster presentation – Immature platelet fraction in ITP is inversely proportional to platelet counts during thrombocytopenic episodes.
- Oral Presentation – Dapsone is an effective agent for refractory ITP: analysis of UK adult ITP registry.

ITP Update Day and ITP Support Association Annual Patient Convention – May 2024

The registry team attended the annual ITP Update Day, held by Hartley Taylor, and the ITP Support Association Annual convention in London. The meetings bring together patients and experts from around the world to discuss the latest developments and updates relating to primary ITP. Dr Chen presented an update on the ITP Registry and Dr McDonald presented an update on the pregnancy registry.



<https://www.qmul.ac.uk/itpregistry/>

Page 3

UK ADULT ITP REGISTRY NEWSLETTER



Issue 011

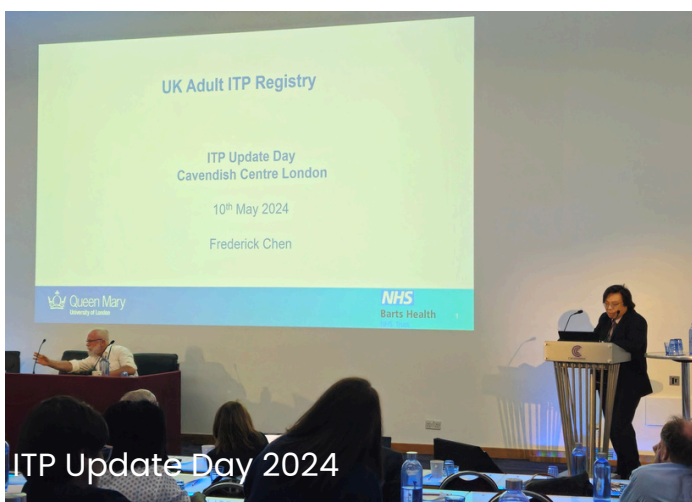
JUL 2024



ITP Support Association Annual Patient Convention 2024



ITP Support Association Annual Patient Convention 2024



ITP Update Day 2024



ITP Update Day 2024

CONTACT DETAILS

Royal London Hospital
2nd Floor Pathology & Pharmacy Building
80 Newark Street,
Whitechapel,
London, E1 2ES

Email: uk-itp.registryteam@nhs.net



Head over to <https://x.com/UKITPR> and support our X (formerly Twitter) page.

We'll be using this platform to shine a light on ITP with the latest news/publications and promote any upcoming events.
#ITPAware
#ITPRegistry!

<https://www.qmul.ac.uk/itpregistry/>