

# THE UK ADULT ITP REGISTRY NEWSLETTER JUL 2022



## WELCOME

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

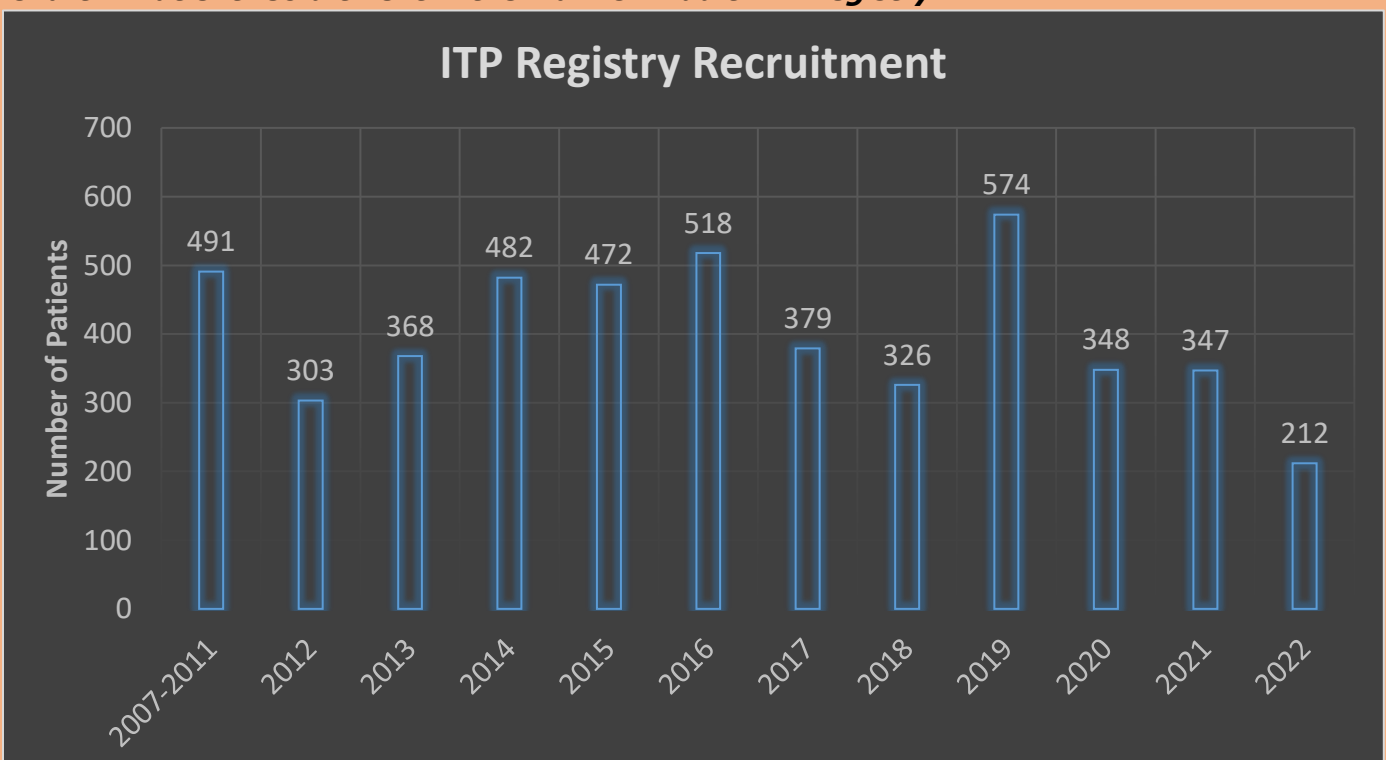


## RECRUITMENT

As of 15<sup>th</sup> July 2022, **4820 patients** have been consented to the Main Registry and **70 patients** have been consented to the pregnancy arm (Charts 1 and 2).

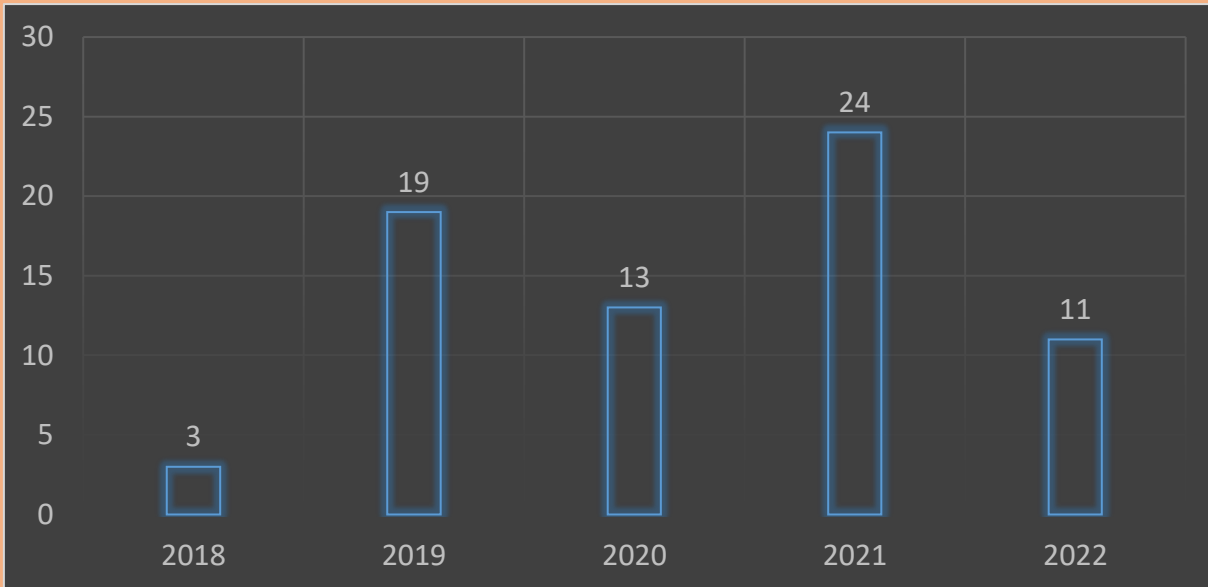
Please continue to send blood samples to the registry for patients who have consented to giving bloods. Remember to remove any patient identifiable information (names and DOBs) from the EDTA tubes; they should only have the Registry Identification Codes and the date the bloods were taken, on them.

**Chart 1. Patient recruitment in the main UK Adult ITP Registry**





**Chart 2. Patient recruitment in the Pregnancy Registry**



70 women have been recruited to the pregnancy arm of the UK Adult ITP Registry since the arm was added in August 2018.

A quick reminder that patients that are currently pregnant and **those who have been pregnant since August 2018 (and meet the inclusion criteria) can be recruited to the registry.**

Participants should be consented for the pregnancy arm in addition to the main arm – the record must exist in both the adult and pregnancy arms.

A screenshot of a REDCap form. At the top, it says 'Total records: 4,712'. Below that, there are two sections: 'Choose an existing Registry Identification Code (RIC)' and 'Enter a new or existing Registry Identification Code (RIC)'. The 'Choose an existing Registry Identification Code (RIC)' section has a dropdown menu with three options: 'Arm 2: Pregnancy Registry' (selected), 'Arm 1: UK ITP Registry', and 'Arm 2: Pregnancy Registry'. The 'Enter a new or existing Registry Identification Code (RIC)' section is empty. A red circle highlights the dropdown menu.

We will soon be approaching 4 years since the beginning of the pregnancy registry and hope to conduct some exciting research! If there are any patients that you have missed consenting during the pandemic, **please consent retrospectively at your earliest convenience – this can be done face to face or remotely.** If you are facing any barriers to recruitment, please let us know and we will work on tackling them with you.

It is really important we have complete data to make meaningful conclusions. Therefore, please review and ensure you enter all data onto REDCap if you haven't done so already (especially for patients that have now given birth and the follow-up data is now available for data entry). If you have any questions, please don't hesitate to reach out to us!

**Thank you for all your hard work.**



## PUBLICATIONS AND PRESENTATIONS



### Trust Open Day – June 2022:

As we ease out of the pandemic, the Barts Health NHS Trust organised several open days across our hospitals to bring our local communities together and promote our work. Our Data Managers (Haroon Miah and Atiqa Miah) engaged with patients and the public whilst raising awareness of ITP and research during a trust open day held at the Royal London Hospital.



### ITP Update Day – May 2022:

The meeting provided an update on clinical aspects of ITP, patient cases were discussed and there was a focus on obstetric and paediatric ITP registries and how to run clinical trials. Dr McDonald presented an update on the ITP Registry.



### ITP Support Association Annual Convention – May 2022:

The annual convention organised by the ITP Support Association brings together patients and experts from around the world to discuss the latest developments and updates relating to primary ITP. Dr McDonald presented 'Trapeze – Patient choices' and provided an update on the ITP Registry.



### ISTH Congress – July 2022

We had a poster presentation at the ISTH congress, titled, 'Paradigm shift in ITP treatment patterns in the era of the COVID-19 pandemic -opportunity to study real world outcomes from an established platform: Update from UK Adult ITP registry'.

In addition, Dr Priyanka Raheja presented, 'Thrombopoietin receptor agonists (TPO-RAs) in older patients with primary immune thrombocytopenia (ITP): effective and safe? Real World Data from the UK adult ITP registry'.



### Publications

Our article, 'Incidence of adult primary immune thrombocytopenia in England — An update', has been published in the European Journal of Haematology. A full list of publications can be found on our website: <https://www.qmul.ac.uk/itpregistry/latest-news-events-and-links/publications-and-presentations/>



## STUDY PROTOCOL & DOCUMENTS



The latest version of the study protocol is version 4.2, 7<sup>th</sup> December 2021.

Below is a table with a list of all the current study Documents in use (a full list of all the study documents can be found on our website, along with previous version).

Document title	Version	Date
UKITPR Study Protocol	4.1	07-Dec-21
UKITPR Participant information sheet (PIS)	5.1	07-Dec-21
UKITPR Pregnancy Participant information sheet (PIS)	2.1	07-Dec-21
UKITPR Study Informed Consent Agreement	6.1	07-Dec-21
UKITPR Pregnancy Study Informed Consent Agreement	1.0	16-May-18
UKITPR Invitation letter to participant and remote consenting	1.0	06-Jul-20
UKITPR Invitation letter to participant and remote consenting - Pregnancy registry	1.0	06-Jul-20
GP/consultant information sheets or letters [UKITPR GP letter template]	1.2	16-May-18



## REDCap DATABASE



**Figure 1. Screenshot of REDCap home screen to show the 'Resolve Issues' link.**

As mentioned previously, please continue to check the 'Resolve Issues' link on REDCap to review which fields/forms have been queried or need completing (Figure 1).

For any questions where the data is missing or unavailable, please enter, '9999' for numeric fields and '01/01/1000' for date fields. Examples can be found in our REDCap user guides.



## CONTACT DETAILS

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

Email: [uk-itp.registryteam@nhs.net](mailto:uk-itp.registryteam@nhs.net)  
Website: [www.qmul.ac.uk/itpregistry](http://www.qmul.ac.uk/itpregistry)



## COMMUNICATIONS

Head over to <https://twitter.com/UKITPR> and support our 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!

You can also visit our Website: <http://www.qmul.ac.uk/itpregistry/>