

THE UK ADULT ITP REGISTRY NEWSLETTER



JUL 2021



WELCOME

Hello and welcome to the latest edition of the UK Adult ITP Registry Newsletter. As sites slowly ease out from study closures put in place to help combat the effects of COVID-19 on NHS resources, this is a great opportunity to update all sites on the latest developments surrounding the Registry and the progress made over the last 12 months.



REDCap DATABASE

We are reviewing the data entered on REDCap, site by site and flagging up any queries or missing data that need to be reviewed/entered by sites. Please ensure to check the 'Resolve Issues' page regularly when you log into REDCap.

If you need any help/clarification on how to use this system, please get in touch.

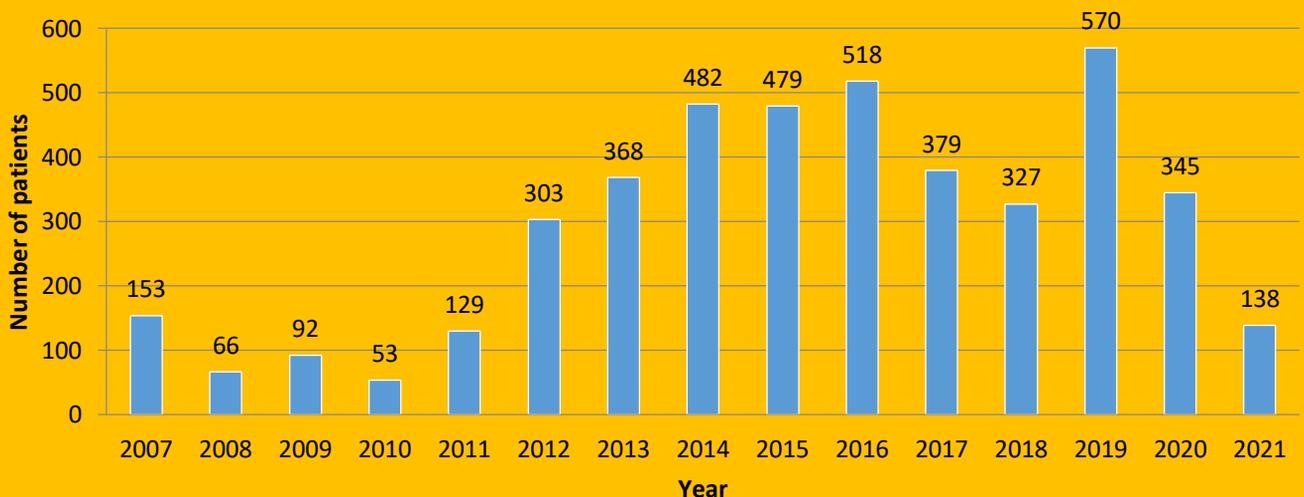


RECRUITMENT

As of 21st July 2021, 4402 patients have been consented to the Registry.

We have sent recruitment dashboards/updates to every site now, giving an overview of your recruitment activity since you joined the study. We're hoping to see an increase of recruitment in the coming months.

ITP Registry Recruitment per year



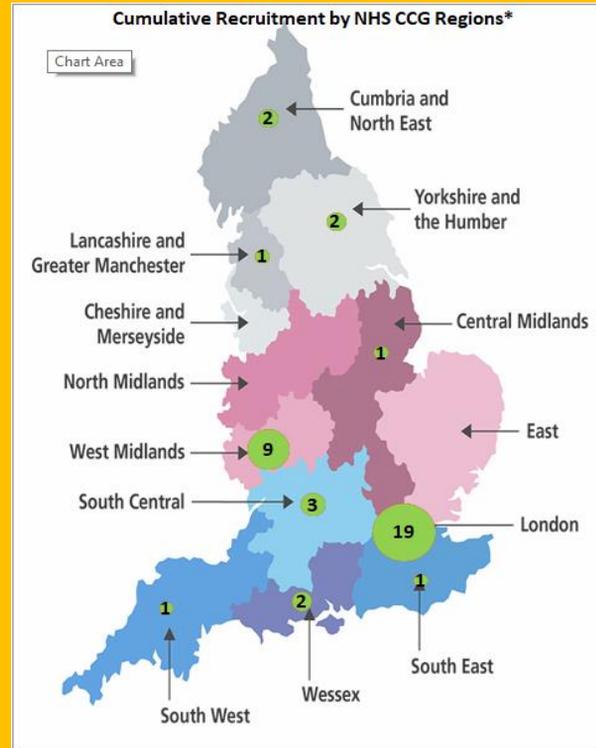


ITP PREGNANCY REGISTRY UPDATES

42 women have been recruited to the pregnancy arm of the UK Adult ITP Registry (see graph below for breakdown of annual recruitment) since the arm was added in August 2018.

Dr Sue Robinson (Co PI) presented analysis of data gathered over the last few years at the ITP Assembly held in May this year and demonstrated its usefulness in providing invaluable insight on the management and outcomes of patients with ITP in pregnancy.

UKITPR Pregnancy Recruitment By Year



UKITPR Pregnancy Recruitment by NHS CCG Regions.

A review of the data most common data resolution queries in April 2021 found that the top 10 most incomplete forms in the pregnancy registry are:

- Pregnancy Registration Details (e.g. date of last period, EDD etc.)
- Problems In Previous Pregnancies
- Anthropometric and Lifestyle Information (e.g. booking weight, history of smoking and alcohol use)
- Bleeding Events During Pregnancy
- ITP Treatments During Pregnancy (e.g. dosing, indication to treat etc.)
- Details Of Delivery and Anaesthesia Method At Delivery
- Haematological Values During Pregnancy
- Coagulation Results At Delivery
- Infant Details, Morbidity, Treatments and Platelet Counts
- Information on Breast Feeding

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. If you have any questions, please don't hesitate to reach out to us!

Thank you for all your hard work.



COVID-19 INDUCED ITP



We updated the UK Adult ITP Registry earlier this year to be able to capture COVID-19 data for any patients who may have been infected with COVID-19. This was incorporated in the Comorbidities section of the database; it is a simple dataset capturing information about the severity of COVID-19 infections with fields to also capture if patients have had a COVID-19 vaccine.

Now that the Oxford-run snapshot audit of management of ITP in the COVID era has finished, for those that took part, this is a good opportunity to add the cases of ITP who have had COVID into the registry!

It is important to note that under the current version of the protocol, patients who have ITP after having a COVID-19 vaccine (no prior confirmation of primary ITP) would not be eligible for the study. However, we are currently working on a substantial protocol amendment that will update the eligibility criteria to include patients who have vaccination induced ITP.

We will keep you updated with any new developments in due course.



RECENT PRESENTATIONS

In May this year, Hartley Taylor hosted the ITP Updates day and the ITP Support Association held their annual convention – both via virtual formats.

From the UK Adult ITP Registry team, Dr McDonald, Dr Robinson, Dr Provan and Prof Newland had dedicated slots at both events, discussing a range of topics, including 'What is the place of splenectomy in ITP', 'What is the place of the newer treatments in ITP', 'Real World Experience in ITP' and updates from both the main Adult ITP Registry and the Pregnancy ITP Registry.

We'd like to take this opportunity to thank the ITP Support Association for continuing to support the UK Adult ITP registry, as well as all the sites who are participating in the study.

For a list of all our publications and presentations, please visit our website on: <https://www.qmul.ac.uk/itpregistry/latest-news-events-and-links/publications-and-presentations/>



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