

THE UK ADULT ITP REGISTRY NEWSLETTER DEC 2021



WELCOME

Hello and welcome to the latest edition of the UK Adult ITP Registry Newsletter. In this edition of the newsletter, we'll give an update on the recruitment activity and discuss the latest substantial protocol amendment and changes to the REDCap database.



RECRUITMENT

As of 30th November 2021, **4562 patients** have been consented to the Main Registry and **55 patients** have been consented to the pregnancy arm (Charts 1 and 2).

Thank you to all the sites who have restarted recruiting new patients to the registry following local pauses due to the COVID-19 restrictions.

Sites are reminded to send through scanned copies of consent forms and updated participants logs after patients consent to the study. Please also upload the recruitment activity on your Local Portfolio Management System (e.g. EDGE, ReDA). If you are sending blood samples, please remove any patient identifiable information and enter the RIC on the EDTA tubes before sending to us.

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

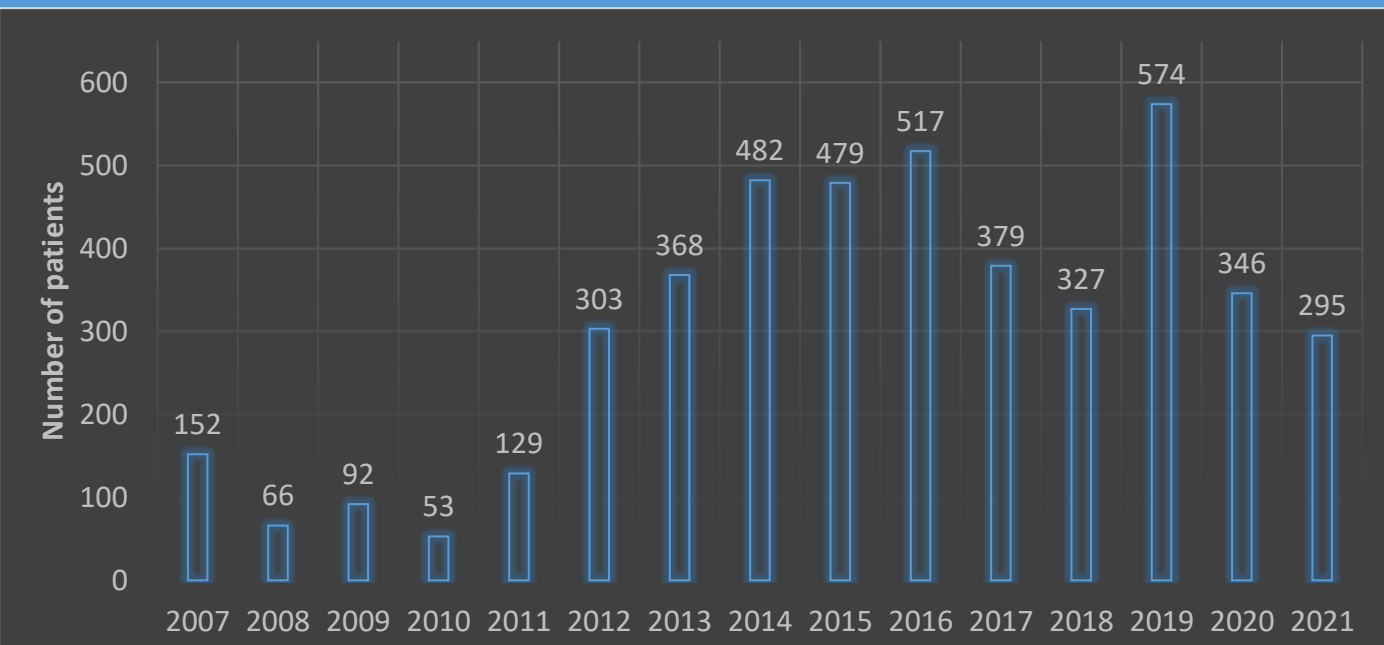


Chart 2. Patient recruitment in the Pregnancy Registry

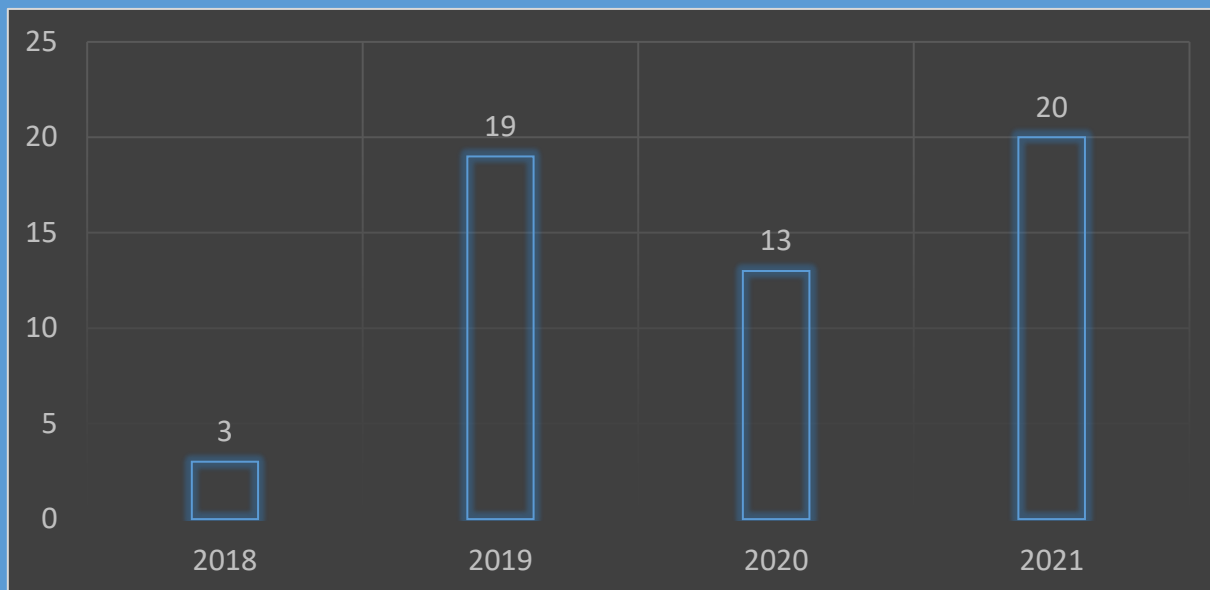


Figure 1. Patient recruitment heatmap in the UK Adult ITP Registry

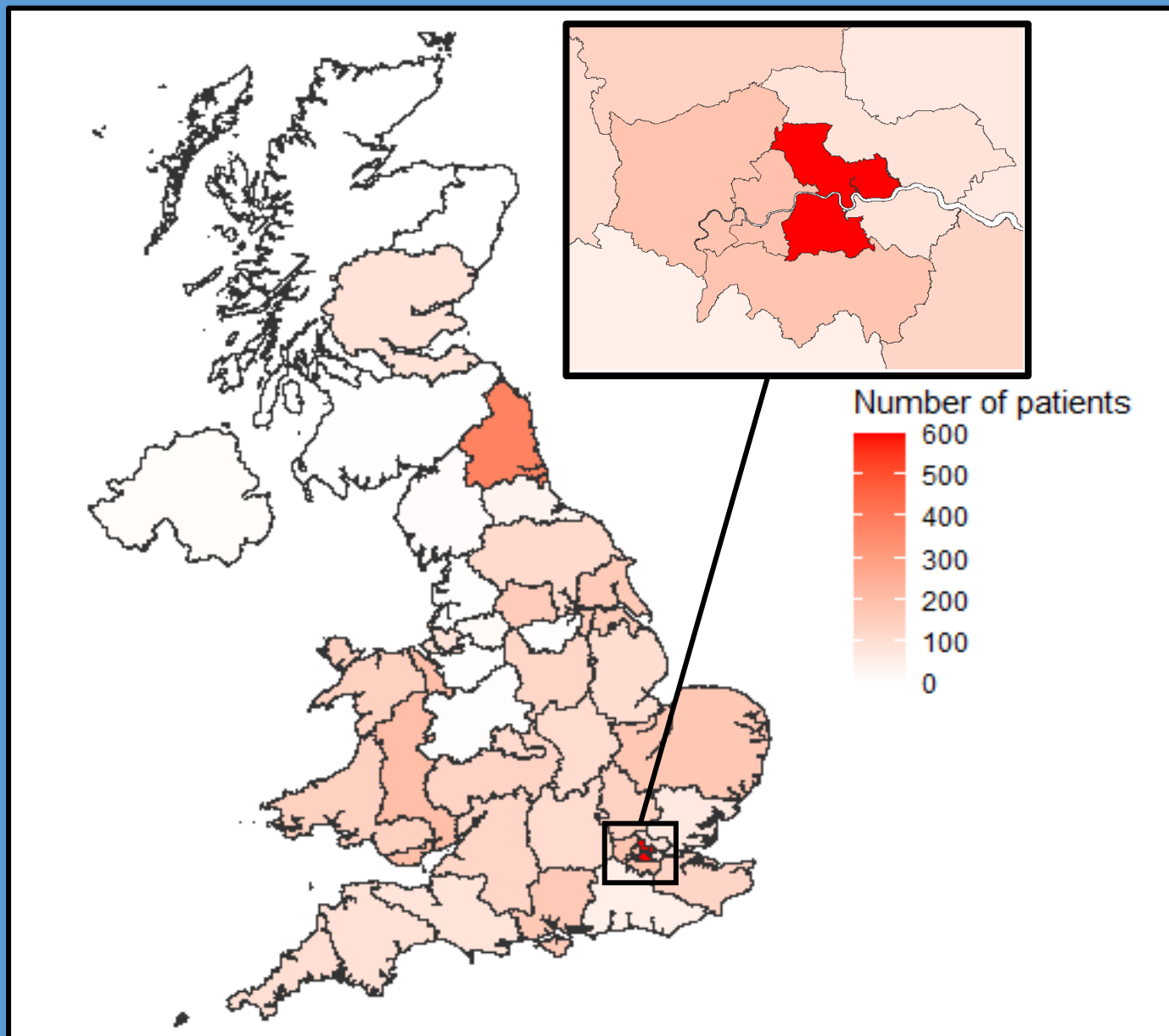




Figure 2. Screenshot of REDCap home screen to show the 'Resolve Issues' link.



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 (Figure 2).

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.



SUBSTANTIAL PROTOCOL AMENDMENT

We have received favourable opinion and HRA/HCRW approval to add **Secondary ITP** to the UK Adult ITP Registry Study.

With this latest substantial protocol amendment (version 4.0), the eligibility criteria has been expanded to include secondary ITP, i.e. cases triggered by other conditions. Work is still ongoing in the background to append the full secondary ITP dataset as a third arm in the registry REDCap database.

Therefore, in the first instance, sites should only consent and capture data on participants where **ITP was seen following a vaccine** (e.g. after a COVID-19 vaccine). This data is captured in the new '**Vaccination History**' form (Figure 3).

There are no changes in the processes to recruit participants with primary ITP and pregnancy ITP. Once all the testing has been completed, the Secondary ITP arm will be added to the REDCap database, where sites will be able to consent and capture data on secondary ITP cases (e.g. Evans syndrome, Lupus, HIV etc.). We will keep all sites updated of any further developments and when this is live.

Figure 3. Screenshot of 'Vaccination History' form from REDCap.

NOTE: To delete the entire record (all forms/events), see the record status page above at top of the Record Home Page.

Advice from the '**UK ITP Forum Vaccine Working Group**' can be found on the BSH website via the following link: <https://b-s-h.org.uk/about-us/news/covid-19-updates/>.

Please continue to support the PHE survey by submitting cases of new or relapsed ITP post COVID-19 <https://snapsurvey.phe.org.uk/snapwebhost/s.asp?k=162574113593>. This will further inform updates of the live document. If clinicians would like to discuss difficult cases related to ITP and COVID-19 vaccination, there is a weekly clinical meeting, Wednesdays at 14:00hrs.

Meeting link:

https://teams.microsoft.com/l/meetup-join/19%3ameeting_MjYyOWQ5OGMtYjE5YS00MTQ2LTk3YjltNzVjNTFIMGZhMTQy%40thead.v2/0?context=%7b%22Tid%22%3a%2237c354b2-85b0-47f5-b222-07b48d774ee3%22%2c%22Oid%22%3a%22ead49e4b-21d0-4ce2-942a-7df928dc069b%22%7d



PUBLICATIONS AND PRESENTATIONS

Some exciting news in terms of outputs from the registry: we will be presenting a poster at the **63rd American Society of Hematology Annual meeting**, 11th to 14th December 2021, on '**How Effective Are the Immunosuppressive Therapies Rituximab and Mycophenolate Mofetil in Immune Thrombocytopenia? Real World Evidence from the UK ITP Registry**'.

Louise Taylor, the lead ITP Nurse at Royal London Hospital, along with Rosie Davies, ITP Nurse at Liverpool, conducted a survey/audit on nurse involvement in ITP care, to get a better understanding of how many centres have nursing support and where additional support could be offered from the ITP nurse network.

If you would like to be included in future nursing ITP activities, including educational meetings, please send your email to:

Rosie Davies: Rosalyn.Davies@liverpoolft.nhs.uk

Louise Taylor: l.taylor6@nhs.net



CONTACT DETAILS

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

Email: uk-ityp.registryteam@nhs.net

Website: www.qmul.ac.uk/itypregistry



CHRISTMAS CLOSURES

The ITP Registry office will be closed from Friday 24th December 2021 to Monday 3rd January 2022 (inclusive). Please do not send any blood samples during this period. We will reopen again on Tuesday 4th January 2022 and will be able to deal with any queries then.

Happy holidays from everyone at the ITP Registry Team.