THE UK ADULT ITP REGISTRY NEWSLETTER

April 2020

WELCOME

Thank you to all the sites for all their hard work on the ITP Registry during this difficult time as the world works through this unprecedented pandemic. It has been a difficult few weeks for all clinical research as hospitals and front line staff work to combat the effects of Covid-19. We appreciate that as a result, research staff who are delegated to work on the ITP Registry may have to be re-deployed to help meet the NHS resource demands locally. We will continue to support all sites who are able to work on the registry and understand that there may be some delays in getting back to us in terms of queries and updates.
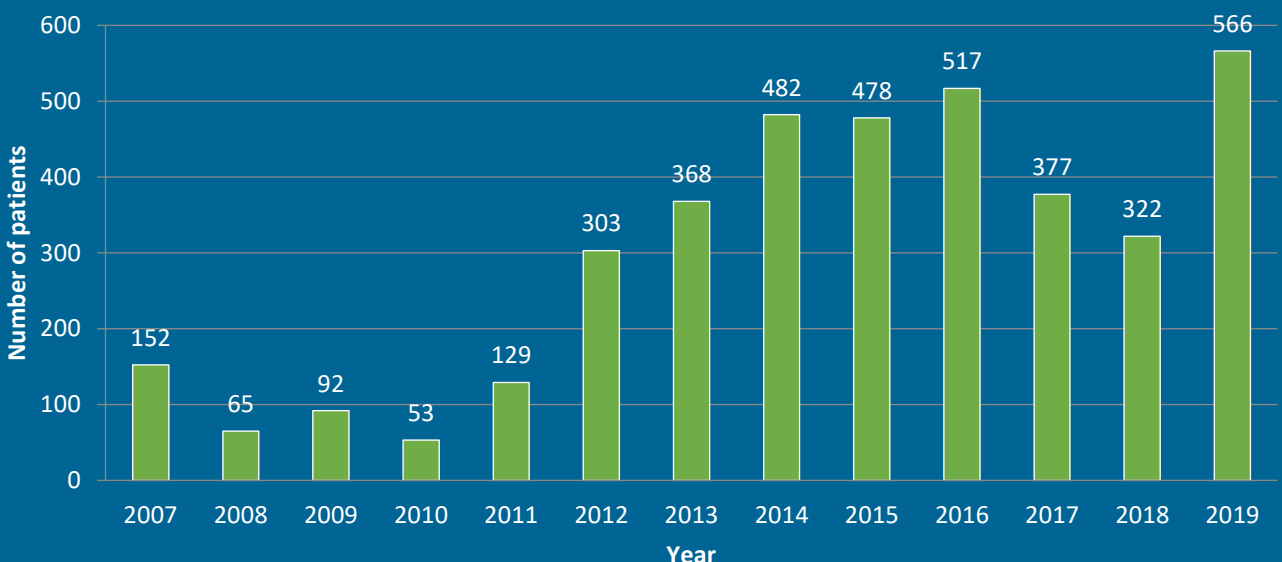
RECRUITMENT

As of 31/03/2020, we have 4074 patients consented in the Registry. We have surpassed all previous years in terms of annual recruitment in 2019. Thank you once again to all sites who have contributed to this.

In addition, we'd like to acknowledge the efforts of all the sites who are working hard to follow up existing patients in the study and may not necessarily be recruiting any new patients. This is just as important!

ITP Registry Recruitment per year

USER FEEDBACK SURVEYS

We had an excellent response to our recent site satisfaction feedback surveys. This is an important exercise for us as it helps us to gauge the experiences of the staff involved in the study and what we can do to provide better help and support.

We will be making a series of changes to the REDCap database and our ITP Registry website over the coming months in light of some of the feedback and comments received from the surveys.

REMINDERS

The **recruitment** period in the study has been extended to **30th June 2022** and the new study end date is **30th June 2023**. The baseline data for each patient is from the **date of diagnosis** (not the date of consent) and patients should be followed up until the study end date.

Once a patient has consented to be a part of the study, please send a scanned copy of the consent form(s), along with the updated version of the participants log spreadsheet for your site to the registry inbox, uk-itp.registryteam@nhs.net. Each site will also have to upload the recruitment activity on their local portfolio management system before the end of each month. This will ensure that all recruitment activity for each site is confirmed on the Central Portfolio Management System (CPMS) without any delay.

Please note, the annual data cut for the submission of research activity on CPMS for the 2019-2020 financial year is on Friday 24/04/2020 at 17.00hrs.

Below is a table of all the current documents and version numbers that should be used:

Document Version Date	Version	Date
UKITPR Study Protocol	2.5	28-Jan-20
Participant information sheet (PIS) [UKITPR prospective participant overview]	3.2	16-May-18
Participant information sheet (PIS) [UKITPR Pregnancy prospective participant overview]	1.1	30-May-19
Participant consent form [UKITPR study informed consent agreement]	4.4	16-May-18
Participant consent form [UKITPR Pregnancy study informed consent]	1	16-May-18
Participant consent form [UKITP Subsequent Tissue Usage Informed Consent Agreement]	1.6	22-Feb-17
UKITP Registry Data Entry Guide on REDCap Database	3.1	29-Nov-19
UKITP Pregnancy Registry - REDCap Database - Data Entry Guide	1.0	29-Aug-18
Other [Initial data collection sheet]	2.6	04-Sep-18
Other [Follow up data collection sheet]	2	04-Sep-18
Other [Pregnancy Registration Sheet]	1.1	04-Sep-18
Other [Pregnancy status and outcome sheet]	1.1	04-Sep-18

REDCap DATABASE

- We will be updating the REDCap database to implement the 'Query Resolution System'. This will enable us to flag up an data entry errors, missing data and queries on the database a lot more readily and easily for users to review. You do not have to do anything at the moment and please continue to enter data on the database as normal. We will update all users when the change is in place.

- The paper proformas were designed to mirror the forms on the REDCap database. These are only for guidance and do not need to be completed as a mandatory activity for the study. They can be used, for example, when you meet a patient in clinic to capture baseline or follow up information. The information can then be transferred onto the online REDCap database when you are near a computer.

- The baseline data for all patients should ideally be entered within 2 months of a patient consenting to the registry. At the very least, the basic demographic data should be entered as soon as possible. If a patient has been entered incorrectly or you have made an error with any form, please contact the Registry team and we will be able to make the necessary corrections.

- The 'Platelet Counts File Upload Function' form isn't working as it should be. Please do not use this form anymore. Instead, complete the Excel template with the platelet count readings and then send the spreadsheet to the Registry team; we will then be able to import the readings for each patient on REDCap.

- The REDCap user guides have step by step instructions on how to enter data for every form on the registry database. Please refer to the guides, in the first instance, if you come across any issues relating to data entry; you will find most of your answers there. If that doesn't help, please escalate to the Registry team.

- The user guides, along with all other study documents can be found on our website, www.ukitpregistry.com.

- If you would like exported data for your site (in csv/Microsoft Excel format), please contact the Registry Team and then we will be able make these available for you.

CONTACT DETAILS

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

Telephone No.: 0203 246 0473
Email: UK-ITP.registryteam@nhs.net

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