

Welcome!

Hello and welcome to the latest issue of the UK Adult ITP Registry newsletter! Thank you to everyone for their ongoing support and working with the registry.

Study Updates

Pregnancy arm of UK ITP Registry

The latest version of the study protocol will now include consenting participants with primary ITP in pregnancy (previously this was an exclusion). Pregnant women diagnosed with primary ITP prior to or during their **current pregnancy** will be consented for the sub-study. It is important to note that this is not a separate study to the main ITP registry and will not require separate R&D approval. Patients who meet the inclusion criteria for the pregnancy arm of the study will have to complete 2 consent forms; one for the main adult ITP registry and the other for the pregnancy registry.

Registry Database

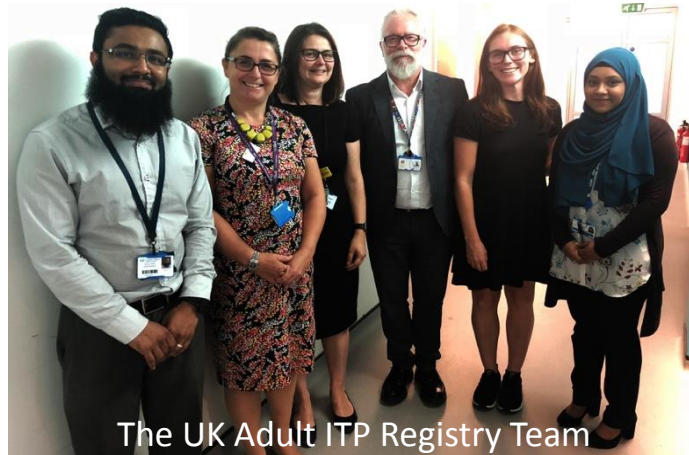
The Registry REDCap database has been successfully updated and is live!

You should have received an email giving you access to the project on REDCap. If you have not received this email or you cannot access the database, please get in touch.

One of the major changes was to incorporate the pregnancy arm of the study, as mentioned above. Please ensure to update your **participant logs** to include a new column titled 'Pregnancy Registry Consent Date'. This is only for participants that consent for the pregnancy arm of the study.

We have updated the user guides and proformas to reflect the latest version of the database – these can be found in the 'File Repository' on REDCap.

For any further information or clarifications, please do not hesitate to contact us.



The UK Adult ITP Registry Team

Reminders

Local approvals for latest substantial protocol amendment:

The HRA notification email was sent to all sites on 06/08/2018 detailing the REC and HRA approvals for the latest substantial protocol amendment along with the document pack.

The new version of the protocol, **version 2.3 dated 16/05/2018**, can now be implemented (as of 10/09/2018). If you haven't done so already, please send through confirmation of your local R&D approvals.

Please send through the localised versions of your patient information sheets and informed consent forms to the registry team.

This is also a great opportunity to send through updated delegation logs and CVs (2 page versions, signed and dated) and GCP certificates.

Recruitment Update

As of 16/10/2018, we have 3252 patients consented to the registry. Below is a table with the 25 sites who have recruited the highest number of patients.

	Hospital	Number consented
1	THE ROYAL LONDON HOSPITAL	281
2	UNIVERSITY COLLEGE HOSPITAL	150
3	SUNDERLAND ROYAL HOSPITAL	123
4	THE ROYAL VICTORIA INFIRMARY	120
5	HAMMERSMITH HOSPITAL	119
6	CASTLE HILL HOSPITAL	110
7	KENT & CANTERBURY HOSPITAL	98
8	NORTHWICK PARK HOSPITAL	94
9	QUEEN ALEXANDRA HOSPITAL	77
10	GLASGOW ROYAL INFIRMARY	71
11	BRADFORD ROYAL INFIRMARY	71
12	THE ROYAL LIVERPOOL UNIVERSITY HOSPITAL	67
13	LEICESTER ROYAL INFIRMARY	66
14	LUTON & DUNSTABLE HOSPITAL	65
15	CHURCHILL HOSPITAL	63
16	NORTH TYNESIDE GENERAL HOSPITAL	62
17	QUEEN'S HOSPITAL	62
18	ST JAMES'S UNIVERSITY HOSPITAL	60
19	ROYAL CORNWALL HOSPITAL (TRELISKE)	57
20	NEVILL HALL HOSPITAL	53
21	WORCESTERSHIRE ROYAL HOSPITAL	52
22	HARROGATE DISTRICT HOSPITAL	51
23	PRINCESS ROYAL UNIVERSITY HOSPITAL	46
24	WEST MIDDLESEX UNIVERSITY HOSPITAL	44
25	MILTON KEYNES HOSPITAL	43

We appreciate the effort from all sites and a full list of sites and recruitment can be found on our website.

UK ITP Registry Contact Details

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

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

The UKITP Registry Website

For the latest updates and developments with the ITP Registry, be sure to visit the UKITP Registry website on <http://ukitpregistry.com>.

You'll also be able to download all the trial documents (current and previous versions); user guides, proformas for the REDCap database and much, much more.