

UKITP Registry Data Entry Database

Terms and Conditions
&
Self-Help Visual Guide



Welcome to the ITP Registry

Thank you for joining the UK ITP registry. The registry will help us investigate pathogenesis, clinical phenotype, treatment effectiveness and co-morbid conditions in patients with ITP.

We know that everyone that helps us collect data is incredibly busy, so thank you for taking the time to use this guide and enter your data onto the database.

If you are having trouble with the database and this guide has not answered your question, please contact us:

email: uk-itp.registryteam@nhs.net

Phone: 020 7377 7000 ext 61114

Our office hours are 9am -5pm, Monday to Friday

Terms and conditions

Before proceeding with the study, you will have been asked to confirm to the ITP Registry team, by email, that you have read, understood and accepted the full terms and conditions of using REDCap, the application which supports the ITP Registry database. Please let us know if you don't have a record of this.

Data Collection

- Only data belonging to participants who have consented to participate in the Registry should be entered on the database (i.e. a signed consent form has been obtained)
- Please ensure that participants meet the eligibility criteria for the study before entering their data

Data Entry Database

- For issues related to data collection and data entry on the database please contact the Registry team uk-ityp.registryteam@nhs.net

Data Sharing

- Centres are able to use their own data for research purposes in line with the Registry's protocol

*please note that all documents, databases and designs that the UKITP Registry uses are copyrighted

Terms and conditions

In order to meet Data Protection regulations, local centres using the ITP registry database need to ensure the following:

- Only staff who are on a delegation log signed by the local Principle Investigator can have access to the database. In order to enter data, the 'data entry' role must be assigned to them on the delegation log.
- The login details, including username and password, should not be shared with anyone who is not the assigned user.
- The database should only be accessed within the trust site where staff are employed
- It is expected that the staff responsible for data entry have undertaken adequate GCP training before entering data on the database

Database data collection forms visual guide

Logging into REDCap



Log In



Welcome to the REDCap service provided by Queen Mary University of London

Published research should cite REDCap as follows:

Study data were collected and managed using REDCap electronic data capture tools hosted at Queen Mary University of London [1]. REDCap (Research Electronic Data Capture) is a secure, web-based application designed to support data capture for research studies, providing 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources.

[1]Paul A. Harris, Robert Taylor, Robert Thielke, Jonathon Payne, Nathaniel Gonzalez, Jose G. Conde, Research electronic data capture (REDCap) - A metadata-driven methodology and workflow process for providing translational research informatics support, J Biomed Inform. 2009 Apr;42(2):377-81.

Please log in with your user name and password. If you are having trouble logging in, please contact [Research IT Support](#).

Username:

Password:

[Forgot your password?](#)

Step 1: Log into REDCap with the log in details provided to you by its-research-support@qmul.ac.uk

Welcome to REDCap!

REDCap is a mature, secure web application for building and managing online surveys and databases. Using REDCap's stream-lined process for rapidly developing projects, you may create and design projects using 1) the online method from your web browser using the Online Designer; and/or 2) the offline method by constructing a 'data dictionary' template file in Microsoft Excel, which can be later uploaded into REDCap. Both surveys and databases (or a mixture of the two) can be built using these methods.

REDCap Features

Build online surveys and databases quickly and securely - Create and design your project rapidly using secure web authentication from your browser. No extra software is required.

Fast and flexible - Conception to production-

Entering the ITP Registry DATABASE



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Listed below are the REDCap projects to which you currently have access. Click the project title to open the project. [View more](#)

Project Title	Records	Fields	Instrument	Type	Status
Multinational Immune Thrombocytopenia Registry_MITP1	743	3,108	20 forms		
Research Management System_MITP1	13	301	4 forms		

The projects listed below are public and are accessible by anyone. No authentication (i.e. username/password) is required to access them directly.

Public Projects
Basic Demography
Classic Database
Human Cancer Tissue Biobank
Longitudinal Database (1 arm)
Longitudinal Database (2 arms)
Multiple Surveys (Classic)

You should have two projects under My Projects:

1. Multinational Immune Thrombocytopenia Registry_MITP . This is where to enter **patient data**.
(It will have a number next to MITP which is for registry team use only)
2. Research Management System_MITP. This is the **staff details** database for your site. Please keep this up-to-date so we can easily contact you.

Entering the ITP Registry DATABASE



Welcome to the REDCap service provided by Queen Mary University of London

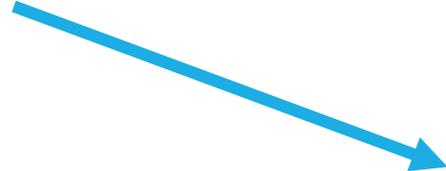
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Click on the project titled
Multinational Immune
Thrombocytopenia Registry_MITP



Project Title	Records	Fields	Instrument	Type	Status
Multinational Immune Thrombocytopenia Registry_MITP1	743	3,108	20 forms		
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Public Projects
Basic Demography
Classic Database
Human Cancer Tissue Biobank
Longitudinal Database (1 arm)
Longitudinal Database (2 arms)
Multiple Sclerosis (clinical)

Adding a new patient

1. Add the new patient to your Participant's Log.

This will automatically assign them the next available Registry Identification Code (RIC).

If you do not have access to a copy of your site Participant Log please email us at uk-itp.registryteam@nhs.net

	A	B	C	D	E	F	G	H
1	Row number	Registry Identification Code (pre-assigned)	ITP Reference Number	Patient Identification Number (PIN)	NHS Number	Participant's Surname	Participant's First name	Participant's Middle Name (if any)
2	1	ABC33216				Bloogs	Joe	
3	3	ABC78447				Doe	Jane	
4	4	ABC99727						
5	7	ABC39450						
6	9	ABC43496						
7	10	ABC97832						
8	11	ABC84824						
9	13	ABC22795						
10	14	ABC60506						
11	15	ABC78056						
12	17	ABC96509						
13	18	ABC58327						
14	19	ABC43643						
15	20	ABC58435						

Adding a new patient

2. click add/edit records

REDCap™
Logged in as CGracie | Log out

My Projects
Project Home
Project Setup
Project status: Development

Data Collection

- Record Status Dashboard
- View data collection status of all records
- Add / Edit Records**
- Create new records or edit/view existing ones

Show data collection instruments ▼

Applications

- Calendar
- Data Exports, Reports, and Stats
- Logging
- Field Comment Log
- File Repository
- DAGs
- E-signature and Locking Mgmt

Help & Information

- Help & FAQ
- Video Tutorials
- Suggest a New Feature

Multinational Immune Thrombocytopenia Registry_test 4

Add / Edit Records

You may view an existing record/response by selecting it from the drop-down lists below. To create a new record/response, type a new value in the text box below and hit Tab or Enter. To quickly find a record without using the drop-downs, the text box will auto-populate with existing record names as you begin to type in it, allowing you to select it.

Total records: 1

Choose an existing Registry Identification Code (RIC)	-- select record -- ▼
Enter a new or existing Registry Identification Code (RIC)	RIC RIC61114

Data Search

Choose a field to search (excludes multiple choice fields)	All fields ▼
Search query 1 Begin typing to search the project data, then click an item in the list to navigate to that record.	

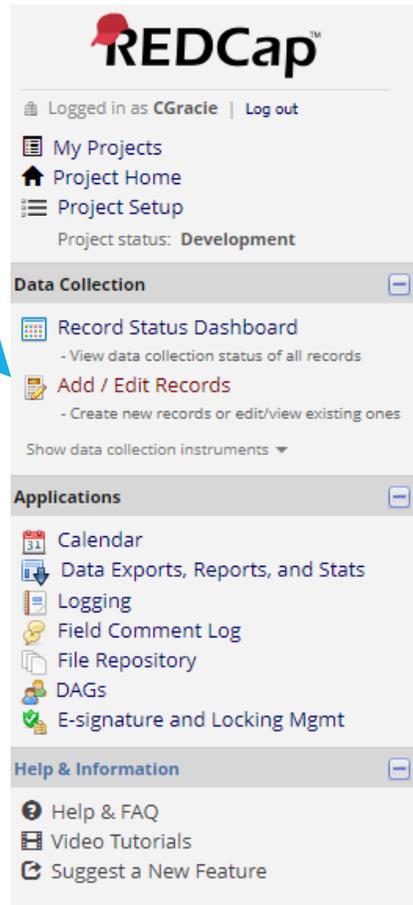
2

NOTICE:
This project is currently in Development status. Real data should NOT be entered until the

3. Type the participant's RIC into box "Enter a new or existing Registry Identification Code (RIC)" and press enter

Accessing an existing patient record

1. click add/edit records



The sidebar contains the following items:

- Logged in as CGracie | Log out
- My Projects
 - Project Home
 - Project Setup
- Project status: Development
- Data Collection
 - Record Status Dashboard
 - View data collection status of all records
 - Add / Edit Records
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Multinational Immune Thrombocytopenia Registry_test 4

Add / Edit Records

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Total records: 1

Choose an existing Registry Identification Code (RIC)	-- select record --
Enter a new or existing Registry Identification Code (RIC)	RIC RIC61114

2. Select the appropriate RIC from the drop down menu box

OR

2. Start to type in the appropriate RIC and click on it as it appears below your typing

Data Search

Choose a field to search (excludes multiple choice fields)	All fields
Search query Begin typing to search the project data, then click an item in the list to navigate to that record.	

NB. It is possible to search for records using other information. The field to be searched needs to be selected before entering the value to be searched.

NOTICE:

This content is currently in Development status. Real data should NOT be entered until the

Adding participant information

REDCap
Logged in as CGracie | Log out
My Projects
Project Home
Project Setup
Project status: Development

Data Collection

- Record Status Dashboard - View data collection status of all records
- Add / Edit Records - Create new records or edit/view existing ones
- Registry Identification Code (RIC) RIC61114 [Select other record](#)

Applications

- Calendar
- Data Exports, Reports, and Stats
- Logging
- Field Comment Log
- File Repository
- DAGs
- E-signature and Locking Mgmt

Help & Information

- Help & FAQ
- Video Tutorials
- Suggest a New Feature
- Contact REDCap administrator

Multinational Immune Thrombocytopenia Registry_test 4

Record Home Page

The grid below displays the form-by-form progress of data entered for the currently selected record. You may click on the colored status icons to access that form/event.

Choose action for record

Registry Identification Code (RIC) **RIC61114**

Legend for status icons:

- Incomplete
- Incomplete (no data saved) ?
- Unverified
- Complete

Data Collection Instrument	Status
Participant Details	Complete
Follow Up Data Collection Status Update	Incomplete
Clinician Information	Incomplete
Anthropometric And Lifestyle Data	Incomplete
Bleeding Events	Incomplete
Itp Treatments	Incomplete
Blood Product Transfusion	Incomplete
Other Itp Treatments	Incomplete
Trial	Incomplete
Cotherapies	Incomplete
Comorbidities	Incomplete
Family History	Incomplete
Biochemical Fields At Itp Diagnosis	Incomplete
Haematological Fields At Itp Diagnosis	Incomplete
Platelet Counts Manual Entry	Incomplete
Platelet Counts File Upload Function	Incomplete
Immunological Fields At Itp Diagnosis	Incomplete
Coagulation Fields At Itp Diagnosis	Incomplete
Bm Aspirate Trephine Biopsy Dat	Incomplete
Comments	Incomplete

You should now be on the “Record Home Page”. Click on the status circle next to the section that you’d like to fill out first.

Redcap uses a traffic light system to record whether each data collection category is complete. You control this system and can choose which colour to mark each section (this will be demonstrated in the next section). This system is for you to track your own records.

Participant Details

Participant Details

Data Access Group: [No]

Save & Exit Form
Save & ...
-- Cancel --

Editing existing Registry Identification Code (RIC) RIC61114

Registry Identification Code (RIC) RIC61114
To rename the record, see the record action drop-down at top of the [Record Home Page](#).

Retype Registry Identification Code (RIC)
* must provide value
RIC61114
Please retype the RIC provided by the Registry

Previous Participant Identification Number (PIN) (if applicable)
PIN generated by the Registry previously

ITP Diagnosis date: 04-12-2017 **Consent Date: 04-12-2017**

Date of Birth
* must provide value
01-01-1917 Today D-M-Y

Participant Age in Years
100 View equation
Participant Current Age (years)

Gender
* must provide value
 Male
 Female
 Uncertain

Ethnicity
British (White)

Participants Country (At Consent)
United Kingdom

Confirm ITP Type
Primary ITP
This registry is for participants diagnosed with Primary ITP. If you are unsure please consult the participant's clinician(s) for clarification.

ITP diagnosis Date
04-12-2017 Today D-M-Y

Participant Age (yrs) at ITP Diagnosis
100 View equation

Consent Date for UKITP Registry
* must provide value
04-12-2017 Today D-M-Y
Date when the participant consented to participate in the Registry. Data should be entered only after consent was obtained. Please make sure that the consent form has been sent to the Registry accompanied with participant's details updated on the Participants' log.

Age at Consent
100 View equation
(years)

Date of this First Data Collection
04-12-2017 Today D-M-Y

When was the last ITP-related clinic visit for this participant?
04-12-2017 Today D-M-Y
this date can be updated after each visit

Retype the RIC here

The 'PIN' will appear here if this patient was on the 'old' database.

Please fill out the participants details.

The First Data Collection Date is usually around when the patient was consented.

The "last ITP-related clinic date" will need updating as the patient attends clinic. It should be the date of the most recent clinic the patient has attended.

Age at Consent (years) view equation

Date of this First Data Collection Today D-M-Y

When was the last ITP-related clinic visit for this participant? Today D-M-Y
this date can be updated after each visit

If this is not the first data collection and all the information required on this page is complete, please proceed to the section 'Follow Up Data Collection Status Update' to state if this is a data update.

Has the participant consented to provide biological sample? Yes No
* must provide value

Biological Samples

Type of sample Please refer to the Registry Sample collection/transfer protocol

Was a biological sample sent ? Yes No

Sample Sent Date Today D-M-Y

Sample Received Date Today D-M-Y
to be updated by the Registry

Form Status

Complete?

Lock this record for this form? Lock
If locked, no user will be able to edit this record on this form until someone with Lock/Unlock privileges unlocks it.

Save & Exit Form Save & Go To Next Form -- Cancel --

Delete data for THIS FORM only

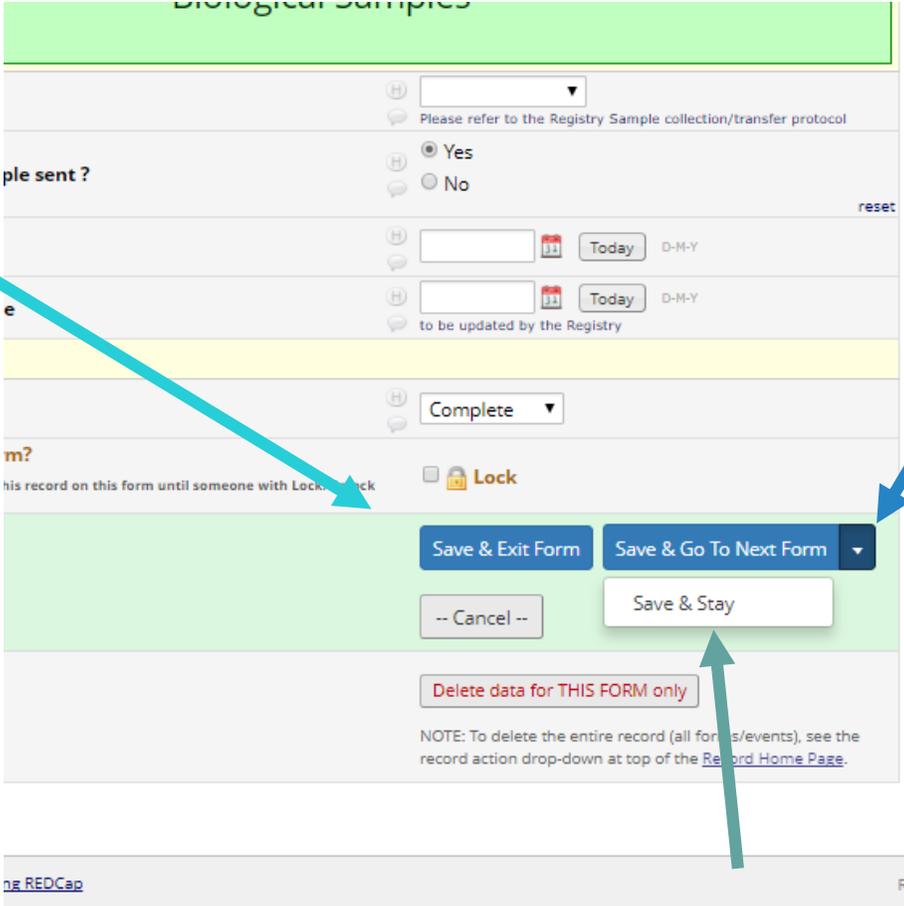
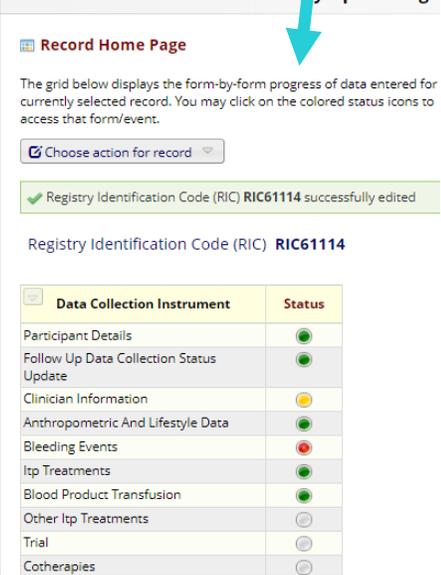
Please fill out the remaining information regarding the patients consent to take part in the registry

The Registry will add the "Sample Received Date"

State whether data entry for this page is complete, incomplete or unverified. What you choose here controls the traffic light system on the record home page, **complete=green, unverified=yellow, incomplete=red.**

Exiting a section of the database

Option 2: Click “Save & Exit Form”. This will take you back to the Record Home Page. From here, you can see which sections you have completed and can choose which section to fill out next



Option 1: Click “Save and go to Next Form”. This will take you to the next form to be filled out for this patient.

NB. the first time you do this the box will say “save &..”. You will have to click on the arrow on the right hand side of the box and set your option as “Save & Go To Next Form”. This will then set the preference as “Save & Go To Next Form”.

Option 3: Click “Save and Stay”. This will save your changes but not change the form. This allows you to review your changes

Follow Up Data Collection Status Update

Multinational Immune Thrombocytopenia Registry_test 4

Actions: [Download PDF of instrument\(s\)](#) [VIDEO: Basic data entry](#)

Follow Up Data Collection Status Update

Data Access Group: [No Assignment] ?

Editing existing Registry Identification Code (RIC) **RIC61114**

Registry Identification Code (RIC) RIC61114

ITP Diagnosis date: 04-12-2017 Consent Date: 04-12-2017

Is this a follow up data collection (i.e. not the initial data collection at registration but the 1st update after)? Yes No

Follow up date 1 Today D-M-Y

What is the current status of the participant?

Add Next Follow-up Data Collection Details (follow up #2)

Form Status

Complete?

Lock this record for this form?

If locked, no user will be able to edit this record on this form until someone with Lock/Unlock privileges unlocks it.

Lock

Save & Exit Form Save & Go To Next Form -- Cancel --

Delete data for THIS FORM only

NOTE: To delete the entire record (all forms/events), see the record action drop-down at top of the [Record Home Page](#).

Step 1: If this is not the first time you are adding data to the registry for this patient, click yes and more boxes will appear below.

Step 2: Select the current status of the participant

Select the completion status, then click "Save & Go To The Next Form"

Haematologist's and GP's details

Multinational Immune Thrombocytopenia Registry_test 4

Actions: [Download PDF of instrument\(s\)](#) [VIDEO: Basic data entry](#)

Clinician Information Data Access Group: [No Assignment] ?

Editing existing Registry Identification Code (RIC) RIC61114

Registry Identification Code (RIC) RIC61114

ITP Diagnosis date: 04-12-2017 Consent Date: 04-12-2017

This page is to guide what information is required and filled in on the participants log, which is sent separately to the Registry

Consultant Haematologist Initials At Consent (e.g. MP for Marco Polo)

Haematologist's Hospital/Centre Name At Consent (please provide all details on participants log)

Was the participant diagnosed as having primary ITP at this centre? Yes No reset
At Diagnosis (if different from At Consent)

Please provide the name, specialty and contact details for this medical practitioner who made this diagnosis on the participants' log

Was the participant referred to your centre for ITP care? Yes No Information Not Available reset

Was the contact details of the General Practitioner entered on the participants' log? Yes No reset
please all details on the participants log

Was the General Practitioner/Family Doctor Proforma sent? Yes No reset

Please use the information received on the GP proforma to assist with the data collection

Was the General Practitioner/Family Doctor Proforma received? Yes No reset

Please use the information received on the GP proforma to assist with the data collection

Form Status

Step 1: Enter the participant's Haematologist's details

Step 2: Select the relevant options. Note that some will require further information

Step 3: Assign completion status and click on "Save & Go To The Next Form"

Anthropometric and lifestyle data

Multinational Immune Thrombocytopenia Registry_test 4

Actions: [Download PDF of instrument\(s\)](#) [VIDEO: Basic data entry](#)

Anthropometric And Lifestyle Data

Data Access Group: [No Assignment]

Editing existing Registry Identification Code (RIC) RIC61114

Registry Identification Code (RIC) RIC61114

ITP Diagnosis date: 04-12-2017 Consent Date: 04-12-2017

Participant Weight
[At diagnosis, or any available adult weight (please check)]

kg

Is the date available? complete date available

Date when weight taken * must provide value

Participant Height
(adult height)

Is the date available?

Participant BMI Equation is [weight in kg / (height in metre)2]

kg/m2

Is the date available?

Obesity Status

Is the date available?

Smoking Status at Consent

Other chewing product habits

Type

Alcohol Consumption

Please ask participant if no information available in medical notes.

Form Status

Step 1: Input the appropriate values using the units specified underneath the white box

Step 2: Select whether the date is available. There are different options according to how specific the date available is. We'd always prefer a full date, but if you only have part of the date then please provide us with what you have. This may be a month and year or just a year.

Step 3: Input the date of the measurement.

Step 4: Assign completion status and click on "Save & Go To The Next Form"

Bleeding Events

Bleeding Events

Data Access Group: [No Assignment] ?

Editing existing Registry Identification Code (RIC) **RIC61114**

Registry Identification Code (RIC)	RIC61114
ITP Diagnosis date: 04-12-2017	Consent Date: 04-12-2017
Bleed Event Type	Purpura
Bleeding Event Date Status	complete date available
Full bleeding event Date	08-12-2017 Today D-M-Y
Bleeding Event Severity	Description of severity of bleed
Bleed Site	Finger - Left Hand (Joint)
Bleed Event Type	<ul style="list-style-type: none">PetechiaePurpuraBruise (traumatic)Bruise (spontaneous) [ecchymosis]HaematomaCutaneous Bleed - UnspecifiedVitreous haemorrhageConjunctival haemorrhageRetinal hemorrhageChoroidal haemorrhage and ruptureSub conjunctival bleedHaemorrhage in Eye - UnspecifiedOral cavity bleedGastrointestinal bleedHaematemesisMelaenaMucocutaneous Bleed Site UnspecifiedEpistaxis (nosebleed)Haemoptysis
Form Status	
Complete?	
Lock this record for this form?	If locked, no user will be able to edit this record on this form until someone with Lock/Unlock privileges unlocks it.

Step 1: Select the appropriate bleed type from the drop down box.

Step 2: Select whether the date is available

Step 3: Enter the date

Step 4: Enter a description of the severity of bleed if available

Step 5: Choose a bleed site from drop down box

Please enter all bleeding events available in the patient's notes

Step 6: Select the completion status, then click "Save & Go To The Next Form"

Can't find the appropriate bleed event or site?

There is an "other option" if you scroll to the bottom of the drop down list. This will allow you to manually enter your own option. We ask you to please check all options before using this. We have tried to include as any possibilities as possible to avoid users choosing this option.

ITP Treatments- Part I: Splenectomy

Itp Treatments

Data Access Group: [No Assignment] ?

Editing existing Registry Identification Code (RIC) RIC61114

Registry Identification Code (RIC) RIC61114

ITP Diagnosis date: 04-12-2017 Consent Date: 04-12-2017

Has this participant had a splenectomy? Yes No reset

Splenectomy Type

Is the treatment date available?

Full Treatment date D-M-Y
* must provide value

ITP Treatment

Form Status

Complete?

Lock this record for this form?
If locked, no user will be able to edit this record on this form until someone with Lock/Unlock privileges unlocks it. Lock

NOTE: To delete the entire record (all forms/events), see the record action drop-down at top of the [Record Home Page](#).

Has the patient had a splenectomy?

Step 1: Click yes or no to specify whether the patient has had a splenectomy

Step 2: If you choose yes, the splenectomy type box will appear. Choose an option from the drop down menu

Step 3: Choose whether the date is available

Step 4: Enter the date

Step 5: Select the completion status, then click "Save & Go To The Next Form"

ITP Treatments- Part II: Other treatments

ITP Treatments

Is the treatment date available? complete date available

Full Treatment date 08-12-2017 Today D-M-Y

* must provide value

ITP Treatment IVIg

IVIg dose 1
g/day (if dose is not in this unit, please convert it to this unit before entering)

Is the start treatment date available? complete date available

Full treatment date 21-08-2017 Today D-M-Y

* must provide value

How long (duration) was this drug prescribed for? 1
Please state in DAYS. A course duration is the length of time that the drug was given over

ITP Treatment

Prednisolone dose

Is the start treatment date available?

Full treatment date

* must provide value

How long (duration) was this drug prescribed for?

ITP Treatment

Form Status

Complete?

Lock this record for this form?
If locked, no user will be able to edit this record on this form until someone with Lock/Unlock privileges unlocks it.

Save & Exit Form Save & Go To Next Form

Step 1: Choose drug from drop down menu

Step 2: Note the unit written below the box and enter the correct dose. The unit will differ for each drug.

Step 3: Enter whether the date is available

Step 4: Add the date

Step 5: Note the unit of the course length which is written the box and enter how long the patient received the drug for. The unit will differ for each drug

Please enter all ITP treatments that are available in the patient's notes

Step 6: Select the completion status, then click "Save & Go To The Next Form"

Blood product transfusions

Multinational Immune Thrombocytopenia Registry_test 4

Actions: [Download PDF of instrument\(s\)](#) [VIDEO: Basic data entry](#)

Blood Product Transfusion

Data Access Group: [No Assignment] ?

Editing existing Registry Identification Code (RIC) **RIC61114**

Registry Identification Code (RIC)	RIC61114
Blood Transfusion Type	Platelets
Platelets dose	<input type="text"/>
Is the start treatment date available?	<input type="text"/>
How long (duration) was this prescribed for?	<input type="text"/>
Blood Transfusion Type	<input type="text"/>
Form Status	<input type="text"/>
Complete?	<input type="text"/>
Lock this record for this form?	<input type="checkbox"/> Lock

If locked, no user will be able to edit this record on this form until someone with Lock/Unlock privileges unlocks it.

Buttons: Save & Exit Form, Save & Go To Next Form, -- Cancel --

Step 1: Use the drop down box to select the type of blood product received

Step 2: Enter number of units

Step 3: Enter whether the date is available

Step 4: Enter for how many consecutive days they received the transfusion.

Step 5: Select the completion status, then click "Save & Go To The Next Form"

Other ITP Treatments- i.e. Protein A Immunoabsorption, H.pylori treatment, Vitamin C Supplements, Plasmapheresis and other

Multinational Immune Thrombocytopenia Registry_test 4

Actions: [Download PDF of instrument\(s\)](#) [VIDEO: Basic data entry](#)

Other Itp Treatments

Data Access Group: [No Assignment] ?

Editing existing Registry Identification Code (RIC) **RIC61114**

Registry Identification Code (RIC) RIC61114

ITP Diagnosis date: 04-12-2017 Consent Date: 04-12-2017

Other ITP Treatment

H. Pylori Treatment dose

Is the start treatment date available?

How long (duration) was this prescribed for?
Please state in DAYS. A course duration is the length of time that the treatment was given over

Other ITP Treatment

Form Status

Complete?

Lock this record for this form?
If locked, no user will be able to edit this record on this form until someone with Lock/Unlock privileges unlocks it.

Step 1: Select the appropriate treatment from the drop down box

Step 2: Enter the dose of the treatment

Step 3: Enter whether the date is available

Step 4: Enter for how long the patient received the treatment

Step 5: Select the completion status, then click "Save & Go To The Next Form"

Trial ITP Treatments

Multinational Immune Thrombocytopenia Registry_test 4

Actions: [Download PDF of instrument\(s\)](#) [VIDEO: Basic data entry](#)

Trial Data Access Group: [No Assignment] ?

Editing existing Registry Identification Code (RIC) RIC61114

Registry Identification Code (RIC) RIC61114

ITP Diagnosis date: 04-12-2017 Consent Date: 04-12-2017

Trial Treatment

MAD Trial dose

Is the trial's treatment date available?

How long (duration) was this prescribed for?

Trial Treatment

Trial Treatment

Trial Treatment

Trial Treatment

Trial Treatment

Form Status

Complete? Incomplete

Lock this record for this form?

If locked, no user will be able to edit this record on this form until someone with Lock/Unlock privileges unlocks it.

Save & Exit Form Save & Go To Next Form -- Cancel --

Step 1: Select the trial the patient is part of

Step 2: Enter the dose of the trial treatment

Step 3: Enter whether the date is available

Step 4: Enter for how many days the patient received the trial treatment.

Step 5: Select the completion status, then click "Save & Go To The Next Form"

Co-therapies - anti-lipids, anti-hypertensives, anti-coagulants, thrombolysis and anti-fibrinolytics

CO -THERAPIES

Cotherapies

Antihypertensive therapy

Name of Anti-hypertensive therapy: Indoramin

Course: Continuous

Start Date Status: complete date available

Full Start Date: 01-12-2015

End Date Status: complete date available

Full End Date: 01-12-2017

CO -THERAPIES

Cotherapies

Anti-lipid therapy

Name of Anti-lipid therapy: Anti-lipid therapy

Course: Anti-hypertensive therapy, Anti-coagulant therapy, Thrombolysis therapy, Anti-fibrinolytic therapy

Start Date Status: [dropdown]

End Date Status: [dropdown]

CO -THERAPIES

Cotherapies

Form Status

Complete?: Incomplete

Lock this record for this form?

Lock

Save & Exit Form Save & Go To Next Form

Step 1: Select the type of co-therapy the patient received

Step 2: Select the name of the specific co-therapy the patient received

Step 3: Enter whether the course was continuous, a one-off or whether it is unknown which of these it was.

Step 4: Enter how much of the start date is available and then enter the start date

Step 5: Enter how much of the end date is available and then enter the end date

Step 6: Select the completion status, then click "Save & Go To The Next Form"

Co-morbidities

The screenshot shows a web-based form for editing an existing Registry Identification Code (RIC) with ID RIC61114. The form includes fields for diagnosis date (04-12-2017) and consent date (04-12-2017). A 'comorbidity' section has a dropdown menu currently set to 'Diabetes, Type 2'. Below this, there are fields for 'Is the comorbidity date available?' (set to 'complete date available') and 'Full comorbidity date' (set to '08-10-2013'). A second 'comorbidity' dropdown menu is open, displaying a list of conditions including Cataracts, Other Eye Conditions, Ear Conditions, Diabetes (Types 1 and 2, Gestational, and unspecified), Hyperthyroidism, Hypothyroidism, Other Thyroid Disorders, Cushing's Syndrome, Other Endocrine Disorders, Hypertension, Gestational Hypertension, and Hypotension. A blue arrow points from the text 'Step 1: Select the co-morbidity from the drop down box' to the open dropdown menu.

Step 1: Select the co-morbidity from the drop down box

Step 2: Select whether the diagnosis date is available

Step 3: Enter as much of the date as is available

Please enter all co-morbidities available in both hospital and GP notes.

Step 4: Select the completion status, then click "Save & Go To The Next Form"

Family History- cancer, ischaemic heart disease, stroke, ITP, autoimmune disease and other

Editing existing Registry Identification Code (RIC) **RIC61114** Save & Go To Next Form

Registry Identification Code (RIC) RIC61114 -- Cancel --

ITP Diagnosis date: 04-12-2017 Consent Date: 04-12-2017

Does the participant have any of the following?

Family history of cancer Yes No Uncertain

Family history of cancer site

Relationship to participant

Add another Family history of Cancer?

Family history of Ischaemic Heart Disease

Family history of Stroke

Family history of ITP

Family History of Other Autoimmune disease No Uncertain Yes

- Acute erythraemia & erythroleukaemia (C940)
- Acute leukaemia of unsp cell type (C950)
- Acute lymphoblastic leukaemia (C910)
- Acute megakaryoblastic leukaemia (C942)
- Acute monocytic leukaemia (C930)
- Acute myelofibrosis (C945)
- Acute myeloid leukaemia (C920)
- Acute myelomonocytic leukaemia (C925)
- Acute panmyelosis (C944)
- Acute promyelocytic leukaemia (C924)
- Adult T-cell leukaemia (C915)
- Alpha heavy chain disease (C881)
- Carcinoma in situ of breast (D05)
- Carcinoma in situ of cervix uteri (D06)
- Carcinoma in situ of middle ear and respiratory system (D02)
- Carcinoma in situ of oral cavity, oesophagus and stomach (D00)
- Carcinoma in situ of other and unspecified digestive organs (D01)
- Carcinoma in situ of other and unspecified genital organs (D07)
- Carcinoma in situ of other and unspecified sites (D09)

There are six questions to complete

If you answer 'yes' to any question additional drop down boxes appear

Step 1: Answer have they had a family history of this type of condition

Step 2: Add specific form of disease e.g. acute myeloid leukaemia for cancer

Step 3: Specify which relation had the disease

Step 4: Repeat for all incidences in the family

Step 5: Select the completion status, then click "Save & Go To The Next Form"

Biochemical Fields at ITP Diagnosis

Biochemical Fields At Itp Diagnosis

Data Access Group: [No Assignment] ?

Editing existing Registry Identification Code (RIC) RIC61114

Registry Identification Code (RIC) RIC61114

ITP Diagnosis date: 04-12-2017 Consent Date: 04-12-2017

Biochemical Fields: At time of diagnosis

Alanine Transaminase (ALT) level (U/L) Level (reference range: 7-40)

Is the date available?

Aspartate Transaminase (AST) Level (U/L) Level (reference range: 13-40)

Is the date available?

Alkaline Phosphatase (ALP) Level (U/L) Level (reference range: 30-130)

Is the date available?

Total Bilirubin Level (umol/L) Level (reference range: < 21)

Is the date available?

Form Status

Complete?

Lock this record for this form? Lock

If locked, no user will be able to edit this record on this form until someone with Lock/Unlock privileges unlocks it.

Please enter ALT, AST, ALP and Bilirubin levels. These values should be obtained as close to the diagnosis date as possible. If you do not have results for these fields close to diagnosis please use what you have, but be sure to specify the date.

Step 1: Enter the blood result making sure it is in the same unit as that stated

Step 2: Select whether the date is available

Step 3: Enter the date

Step 4: Select the completion status, then click "Save & Go To The Next Form"

Haematological Fields at ITP Diagnosis

Data Access Group: [No]

Editing existing Registry Identification Code (RIC) **RIC61114**

Registry Identification Code (RIC) RIC61114

ITP Diagnosis date: 04-12-2017 Consent Date: 04-12-2017

Haemoglobin Count (Level at Diagnosis)	<input type="text"/>	reference range: Male: 13.0 - 18.0 g/dL Female: 11.5 - 16.5 g/dL
Is the date available?	<input type="text"/>	
Neutrophils Count (Level at Diagnosis) (x10 ⁹ /L)	<input type="text"/>	reference range: 1.8 - 7.5
Is the date available?	<input type="text"/>	
White Blood Cells Count (Level at Diagnosis) (x10 ⁹ /L)	<input type="text"/>	reference range: 4 - 11
Is the date available?	<input type="text"/>	
Red Blood Cells Count (Level at Diagnosis) (x10 ¹² /L)	<input type="text"/>	reference range: Male: 3.97 - 5.54 /pL Female: 3.66 - 4.9 /pL
Is the date available?	<input type="text"/>	
Mean Platelet Volume (MPV) [Volume at Diagnosis]	<input type="text"/>	Count
Is the date available?	<input type="text"/>	
Blood Group	<input type="radio"/> O <input type="radio"/> AB <input type="radio"/> A <input type="radio"/> B <input type="radio"/> Unknown/Untested	reset
Is the date available?	<input type="text"/>	

As with “Biochemical Fields at ITP Diagnosis”, please use the results which are closest to the time of ITP diagnosis and remember to specify the date the results were obtained.

Step 1: Enter the blood result making sure it is in the same unit as that stated

Step 2: Select whether the date is available

Step 3: Enter the date

Step 4: Select the completion status, then click “Save & Go To The Next Form”

Platelet Counts Manual Entry

Multinational Immune Thrombocytopenia Registry_test 4

Actions: [Download PDF of instrument\(s\)](#) [VIDEO: Basic data entry](#)

Platelet Counts Manual Entry Data Access Group: [No Assignment] ?

Editing existing Registry Identification Code (RIC) **RIC61114**

Registry Identification Code (RIC) RIC61114

*** Platelet counts required from at least 3 months before ITP diagnosis up to latest update. If more than 3 months before ITP diagnosis available and too many to enter manually please use the platelet count data upload function on the next tab**

Add Platelet Count

Platelet Count date status

Full date of Platelet Count Today D-M-Y

* must provide value

Add Platelet Count

Platelet Count date status

Form Status

Complete?

Lock this record for this form? **Lock**

If locked, no user will be able to edit this record on this form until someone with Lock/Unlock privileges unlocks it.

NOTE: To delete the entire record (all forms/events), see the

Step 1: Enter the platelet count (unit= x10⁹/l)

Step 2: Select whether the date is available

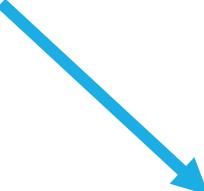
Step 3: Enter the date

If there are too many platelet counts to enter manually, please use the excel spreadsheet which you can upload (shown on the next page).

Step 4: Select the completion status, then click "Save & Go To The Next Form"

Platelet Counts File Upload Function: downloading template

Step 1: Click on “File Repository” under the “Applications” bar on the left hand side



REDCap
Logged in as CGracie | Log out
My Projects
Project Home
Project Setup
Project status: Production
Data Collection
Record Status Dashboard
Add / Edit Records
Show data collection instruments
Applications
Calendar
Data Exports, Reports, and Stats
Logging
Field Comment Log
File Repository
DACS
E-signature and Locking Mgmt
Project Bookmarks
Research Management System (Centre's Details)
Help & Information
Help & FAQ
Video Tutorials
Suggest a New Feature
Contact REDCap administrator



Queen Mary, University of London
Research ITS

Multinational Immune Thrombocytopenia Registry_MITP1

File Repository

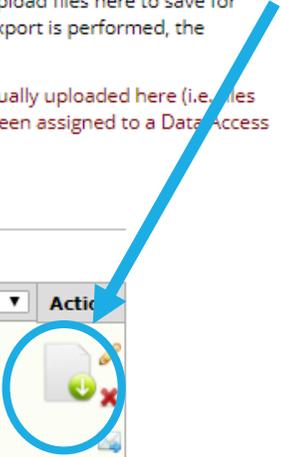
This page may be used for storing and retrieving files and documents used for this project. You may upload files here to save for retrieval later, or you may download previously uploaded files in the file list below. Whenever a data export is performed, the resulting data and syntax files are stored here also.

NOTE: Since Data Access Groups have been created in this project, please be aware that any files manually uploaded here (i.e. files listed under User Files) will be available to ALL project users, regardless of whether they or you have been assigned to a Data Access Group or not.

User Files | Data Export Files | Upload New File

	Filter by file type: ALL	Action
PlateletCount_Template_for_upload File name: PlateletCount_EnterSiteNameHere_EnterDateHere.xlsx Date uploaded: 19/07/2017 File size: 8.1 KB		

Step 2: Click on the download symbol next to “PlateletCount_Template_for_upload”



Platelet Counts File Upload Function: filling out template

Step 3: Fill out the template as this example has been

	A	B	C	D	E	F
1	Registry Identification Code (RIC)	Platelet Count (platelet_ct)	Date (platelet_dt)			
2	ABC12345	100	01/01/2001			
3	ABC12345	35	02/01/2001			
4	ABC12345	10	03/01/2001			
5	ABC12345	9	04/01/2001			
6	ABC12345	15	05/01/2001			
7	ABC12345	25	06/01/2001			
8	ABC12345	60	07/01/2001			
9	ABC12345	65	08/01/2001			
10	ABC12345	67	09/01/2001			
11	ABC12345	59	10/01/2001			
12	ABC12345	60	11/01/2001			
13	ABC12345	30	12/01/2001			
14	ABC12345	27	13/01/2001			
15	ABC12345	23	14/01/2001			
16	ABC12345	25	15/01/2001			
17	ABC12345	21	16/01/2001			
18	ABC12345	86	17/01/2001			
19	ABC12345	90	18/01/2001			
20	ABC12345	100	19/01/2001			
21	ABC12345	98	20/01/2001			
22						

RIC in every row



Date the platelet count was measured as short date format



Step 4: Save the template. Make sure the name includes the RIC of the patient

Platelet Counts File Upload Function: uploading template

Step 5: Click on "Platelet Counts File Upload Function"

The screenshot shows the REDCap interface for the 'Multinational Immune Thrombocytopenia Registry_test 4'. The left sidebar contains a 'Data Collection' section with various data collection instruments. The 'Platelet Counts File Upload Function' is highlighted in the sidebar. The main content area displays the 'Platelet Counts File Upload Function' page, which includes a form for editing an existing Registry Identification Code (RIC) and instructions for uploading a template. The 'Upload document' button is circled in blue. A file upload dialog box is open, showing the selected file 'PlateletCoun...ec2017.xlsx' and the 'Upload document' button.

Step 6: Click on "Upload Document"

Step 7: This box will appear. Click choose file, find the file and click open

Step 8: Click on "Upload Document"

Platelet Counts File Upload Function: uploading template

Platelet Counts File Upload Function

Data Access Group: [No]

Editing existing Registry Identification Code (RIC) RIC61114

Registry Identification Code (RIC) RIC61114

ITP Diagnosis date: 04-12-2017 Consent Date: 04-12-2017

Platelet Count Upload Excel Template

1. Please use this template to fill in the platelet counts for this participant only.
2. Some centres can download this from their laboratory results system or can copy and paste onto this template.
3. After you have obtained all the platelet counts and their respective dates, please upload below.

Please upload platelet counts here ==>

[PlateletCount_ABC12345_01Dec2017... \(0.01 MB\)](#)

* must provide value

Remove file or Send-It

click on link above, locate the file using browse, then upload

Please download the below platelet counts file

Use the template below by clicking on the attachment
The excel sheet can be used to load all the platelet count data
Save the excel sheet in folder where you can locate it
Click on 'Upload Document'
Find the excel sheet under browse and select it before clicking on 'upload document'
Do not forget to save page when finished
and
send a copy of this excel sheet with the platelet count to
uk-itp.registryteam@nhs.net
with subject title in the email: Platelet Count Upload Copy

Date of upload 12-12-2017 Today D-M-Y

Form Status

Step 9: Make sure you can see the uploaded document here

Step 10: Select the completion status, then click "Save & Go To The Next Form"

Immunological Fields at ITP Diagnosis

Multinational Immune Thrombocytopenia Registry_test 4

Actions: [Download PDF of instrument\(s\)](#) [VIDEO: Basic data entry](#)

Immunological Fields At Itp Diagnosis Data Access Group: [No Assignment] ?

Editing existing Registry Identification Code (RIC) **RIC61114**

Registry Identification Code (RIC) RIC61114
ITP Diagnosis date: 04-12-2017 Consent Date: 04-12-2017

Immunoglobulin

IgG reference range (mg/dl): 639 - 1349
Is the date available?

IgM reference range (mg/dl): 56 - 352
Is the date available?

IgA reference range (mg/dl): 70 - 312
Is the date available?

Anti-Nuclear Antibodies Level
Is the date available?

Form Status

Complete? Incomplete

Lock this record for this form? Lock
If locked, no user will be able to edit this record on this form until someone with Lock/Unlock privileges unlocks it.

Save & Exit Form Save & Go To Next Form -- Cancel --

Please give whichever set of results you have available that are closest in time to the ITP diagnosis date

Step 1: Enter the result making sure it is in the same unit as those stated

Step 2: Select whether the date is available

Step 3: Enter the date

Step 4: Select the completion status, then click "Save & Go To The Next Form"

Coagulation Field at ITP Diagnosis

Registry Identification Code (RIC)	RIC61114	Save & Exit Form
ITP Diagnosis date: 04-12-2017	Consent Date: 04-12-2017	Save & Go To Next Form
Prothrombin Time (PT) (Seconds)	<input type="text"/>	-- Cancel --
	reference range: 8.8 - 11.7	
PT Reference Value	<input type="text"/>	
PT Ratio	<input type="text"/>	
Is the date available?	<input type="text"/>	
Activated Partial Thromboplastin Time (APTT)	<input type="text"/>	
	reference range: 21 - 34	
APTT lower time	<input type="text"/>	
APTT higher time	<input type="text"/>	
Is the date available?	<input type="text"/>	
Reticulocyte Percentage	<input type="text"/>	
Is the date available?	<input type="text"/>	
Lupus Anticoagulant (LA) Result	<input type="text"/>	
	Level	
Is the date available?	<input type="text"/>	
Anticardiolipin Antibody (aCl) - IgG	<input type="text"/>	
Is the date available?	<input type="text"/>	
Anticardiolipin Antibody (aCl) - IgM	<input type="text"/>	
Is the date available?	<input type="text"/>	
Form Status		
Complete?	Incomplete	

Please give whichever set of results you have available that are closest in time to the ITP diagnosis date

Step 1: Enter the result making sure it is in the same unit as those stated

Step 2: Enter other values specified if available to you

Step 3: Select whether the date is available

Step 4: Enter the date

Step 5: Select the completion status, then click "Save & Go To The Next Form"

BM Aspirate, Trephine Biopsy & DAT

Editing existing Registry Identification Code (RIC) RIC61114

Registry Identification Code (RIC) RIC61114

ITP Diagnosis date: 04-12-2017 Consent Date: 04-12-2017

Has the participant had any of those?

Bone Marrow Aspirate

Yes
 No
 Uncertain

Is the date available?

Marrow Aspirate Conclusion

Trephine Biopsy

Free Text
Results consistent with ITP
Results inconsistent with ITP
Inconclusive Results
Not Tested
Not Available

Is the date available?

Direct Agglutination Test (DAT) Result at Diagnosis

Positive
 Negative
 Not tested
 NA

Is the date available?

Indium Scanning (At Consent and Follow up)

Yes
 No
 Uncertain

Is the date available?

Form Status

Data Access Group: [No] Save & Exit Form Save & Go To Next Form -- Cancel --

Step 1: Click Yes/NO/ Uncertain to show whether they have had the procedure. More options will appear if you click yes.

Step 2: Select whether the date is available

Step 3: Enter the date

Step 4: Choose the conclusion from the drop down box

Step 5: Select the completion status, then click "Save & Go To The Next Form"

Comments

Data Access Group: [No] Save & Exit Form
Save & Stay
-- Cancel --

Editing existing Registry Identification Code (RIC) **RIC61114**

Registry Identification Code (RIC) RIC61114
ITP Diagnosis date: 04-12-2017 Consent Date: 04-12-2017

Other Comments		<div style="border: 1px solid #ccc; height: 40px;"></div>	Expand
<small>other comments</small>			
Other Comments		<div style="border: 1px solid #ccc; height: 40px;"></div>	Expand
<small>other comments</small>			
Other Comments		<div style="border: 1px solid #ccc; height: 40px;"></div>	Expand
<small>other comments</small>			
Other Comments		<div style="border: 1px solid #ccc; height: 40px;"></div>	Expand
<small>other comments</small>			
Other Comments		<div style="border: 1px solid #ccc; height: 40px;"></div>	Expand
<small>other comments</small>			

This final page is for you to add anything extra that you think we should know about the patient.

Select the completion status, then click “Save & Go To The Next Form”

Finished record

The screenshot shows the REDCap Record Home Page for record RIC61114. The page includes a sidebar with navigation options like 'My Projects', 'Data Collection', and 'Applications'. The main content area displays a 'Record Home Page' with a legend for status icons: Incomplete (red dot), Incomplete (no data saved) (grey dot), Unverified (yellow dot), and Complete (green dot). A green notification bar indicates 'Registry Identification Code (RIC) RIC61114 successfully edited'. Below this, a table lists various data collection instruments, all of which have a green 'Complete' status icon.

Data Collection Instrument	Status
Participant Details	Complete
Follow Up Data Collection Status Update	Complete
Clinician Information	Complete
Anthropometric And Lifestyle Data	Complete
Bleeding Events	Complete
Itp Treatments	Complete
Blood Product Transfusion	Complete
Other Itp Treatments	Complete
Trial	Complete
Cotherapies	Complete
Comorbidities	Complete
Family History	Complete
Biochemical Fields At Itp Diagnosis	Complete
Haematological Fields At Itp Diagnosis	Complete
Platelet Counts Manual Entry	Complete
Platelet Counts File Upload Function	Complete
Immunological Fields At Itp Diagnosis	Complete
Coagulation Fields At Itp Diagnosis	Complete
Bm Aspirate Trepine Biopsy Dat	Complete

At the end of adding patient data you should end up with “Record home page” which looks like this. This patient record is now complete.

We ask that every patient is followed up at least annually, but it is up to you if you wish to do it more frequently. Clinic visits offer convenient times to add more data for the patient. With each subsequent addition of data, you only need to add the new information. Do not delete the data that is already there, simply add the extra events at the end of the form.

Thank you for taking the time to add your patient data to our database.

For any queries with regards to data entry not addressed in this set of slides please contact the registry team at uk-itp.registryteam@nhs.net
or call 02073 777 000 ext 61114 9am-5pm, Mon-Fri