

# 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](mailto: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-itp.registryteam@nhs.net](mailto:uk-itp.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?](#)

## 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-

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

# 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. [Read more](#)

My Projects <span>Organize</span>					
Filter projects by title					
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.

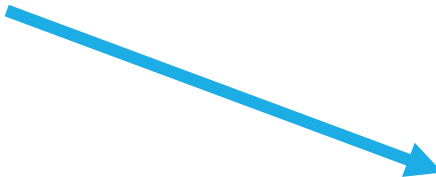
Public Projects
Basic Demography
Classic Database
Human Cancer Tissue Biobank
Longitudinal Database (1 arm)
Longitudinal Database (2 arms)
Multiple Surveys (classic)

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

Click on the project titled  
Multinational Immune  
Thrombocytopenia Registry\_MITP



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Public Projects
Basic Demography
Classic Database
Human Cancer Tissue Biobank
Longitudinal Database (1 arm)
Longitudinal Database (2 arms)
Multimedia Survey (classic)



# Adding a new patient

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

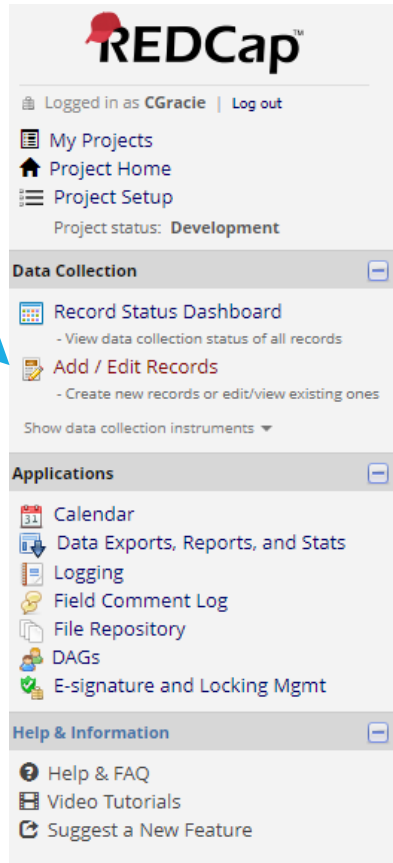
This will automatically assign them the next available Registry Identification Code (RIC).

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



The sidebar menu of the REDCap interface. It includes the REDCap logo at the top, followed by a login status bar showing 'Logged in as CGracie' and a 'Log out' link. Below this are sections for 'My Projects' (Project Home, Project Setup), 'Data Collection' (Record Status Dashboard, Add / Edit Records), 'Applications' (Calendar, Data Exports, Reports, and Stats, Logging, Field Comment Log, File Repository, DAGs, E-signature and Locking Mgmt), and '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)	<input type="text" value="RIC"/> <div>RIC61114</div>

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

Data Search	
Choose a field to search (excludes multiple choice fields)	All fields
Search query 1	<input type="text"/>
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

# Accessing an existing patient record

1. click  
add/edit  
records

The sidebar menu on the left of the REDCap interface. It includes the REDCap logo at the top, followed by a 'Logged in as CGracie | Log out' link. Below this are sections for 'My Projects' (Project Home, Project Setup), 'Data Collection' (Record Status Dashboard, Add / Edit Records), 'Applications' (Calendar, Data Exports, Reports, and Stats, Logging, Field Comment Log, File Repository, DAGs, E-signature and Locking Mgmt), and '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-down, 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)	<input type="text" value="RIC"/> <div>RIC61114</div>

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.	<input type="text"/>

1

2

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

My Projects

Project Home

Project Setup

Project status: Development

Data Collection

Record Status Dashboard

Add / Edit Records

Registry Identification Code (RIC)

RIC61114

Select other record

Data Collection Instruments:

Participant Details

Follow Up Data Collection Status Update

Clinician Information

Anthropometric And Lifestyle Data

Bleeding Events

Itp Treatments

Blood Product Transfusion

Other Itp Treatments

Trial

Cotherapies

Comorbidities

Family History

Biochemical Fields At Itp Diagnosis

Haematological Fields At Itp Diagnosis

Platelet Counts Manual Entry

Platelet Counts File Upload Function

Immunological Fields At Itp Diagnosis

Coagulation Fields At Itp Diagnosis

Bm Aspirate Trepine Biopsy Dat

Comments

Lock all instruments

Applications

Calendar

Data Exports, Reports, and Stats

Logging

Field Comment Log

File Repository

DAGs

E-signature and Locking Mgmt

Help & Information

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)

RIC61114

\* must provide value

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

01-01-1917

Today

D-M-Y

\* must provide value

Participant Age in Years

100

View equation

Participant Current Age (years)

Gender

Male

Female

Uncertain

\* must provide value

Ethnicity

British (White)

reset

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

04-12-2017

Today

D-M-Y

\* must provide value

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	<input type="text" value="100"/> (years)	view equation	Save & Exit Form
Date of this First Data Collection	<input type="text" value="04-12-2017"/> Today D-M-Y		Save & Go To Next Form
When was the last ITP-related clinic visit for this participant?	<input type="text" value="04-12-2017"/> Today D-M-Y <small>this date can be updated after each visit</small>		-- Cancel --
<div>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.</div>			
Has the participant consented to provide biological sample?	<input checked="" type="radio"/> Yes <input type="radio"/> No	reset	
<div>Biological Samples</div>			
Type of sample	<input type="text"/> Please refer to the Registry Sample collection/transfer protocol		
Was a biological sample sent ?	<input checked="" type="radio"/> Yes <input type="radio"/> No	reset	
Sample Sent Date	<input type="text"/> Today D-M-Y		
Sample Received Date	<input type="text"/> Today D-M-Y <small>to be updated by the Registry</small>		
Form Status			
Complete?	<input type="text" value="Complete"/>		
Lock this record for this form?	<input type="checkbox"/> Lock <small>If locked, no user will be able to edit this record on this form until someone with Lock/Unlock privileges unlocks it.</small>		
<div>Save &amp; Exit Form Save &amp; Go To Next Form -- Cancel --</div>			
<div>Delete data for THIS FORM only</div>			

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

**Record Home Page**

The grid below displays the form-by-form progress of data entered for 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 successfully edited

Registry Identification Code (RIC) RIC61114

Data Collection Instrument	Status
Participant Details	●
Follow Up Data Collection Status Update	●
Clinician Information	●
Anthropometric And Lifestyle Data	●
Bleeding Events	●
Itp Treatments	●
Blood Product Transfusion	●
Other Itp Treatments	●
Trial	●
Cotherapies	●

Biological Samples

Please refer to the Registry Sample collection/transfer protocol

Sample sent ? ☒ Yes ☐ No

Today Today D-M-Y D-M-Y

to be updated by the Registry

Complete

Lock

his record on this form until someone with Lock

Save & Exit Form Save & Go To Next Form

-- Cancel -- Save & Stay

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.

**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?**

complete date available  
only month & year available  
only year available  
no date available but occurred BEFORE ITP diagnosis  
no date available but occurred AFTER ITP diagnosis  
no date & unable to determine if occurred before or after ITP diagnosis

**Participant BMI** Equation is [weight in kg / (height in metre)<sup>2</sup>]

kg/m<sup>2</sup>

**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	<div>Petechiae Purpura Bruise (traumatic) Bruise (spontaneous) [ecchymosis] Haematoma Cutaneous Bleed - Unspecified Vitreous haemorrhage Conjunctival haemorrhage Retinal hemorrhage Choroidal haemorrhage and rupture Sub conjunctival bleed Haemorrhage in Eye - Unspecified Oral cavity bleed Gastrointestinal bleed Haematemesis Melaena Mucocutaneous Bleed Site Unspecified Epistaxis (nosebleed) Haemoptysis</div>
Form Status	
Complete?	
Lock this record for this form? <small>If locked, no user will be able to edit this record on this form until someone with Lock/Unlock privileges unlocks it.</small>	

**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**

<b>Registry Identification Code (RIC)</b>	RIC61114
<b>ITP Diagnosis date: 04-12-2017</b>	<b>Consent Date: 04-12-2017</b>
<b>Has this participant had a splenectomy?</b>	<input checked="" type="radio"/> Yes <input type="radio"/> No
<b>Splenectomy Type</b>	Laparoscopic
<b>Is the treatment date available?</b>	complete date available
<b>Full Treatment date</b> <small>* must provide value</small>	<input type="text"/>  Today D-M-Y
<b>ITP Treatment</b>	<input type="text"/>
<b>Form Status</b>	
<b>Complete?</b>	Incomplete
<b>Lock this record for this form?</b> <small>If locked, no user will be able to edit this record on this form until someone with Lock/Unlock privileges unlocks it.</small>	
<input type="checkbox"/>  <b>Lock</b>	
<div> <div>Save &amp; Exit Form</div> <div>Save &amp; Go To Next Form</div> </div> <div>-- Cancel --</div>	
<div>Delete data for THIS FORM only</div>	
<small>NOTE: To delete the entire record (all forms/events), see the record action drop-down at top of the <a href="#">Record Home Page</a>.</small>	

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

The screenshot shows a web-based form for recording ITP treatments. It contains several sections for different treatments. The first section is for IVIg treatment, and the second is for Prednisolone treatment. Blue arrows point to specific fields with corresponding step numbers:

- Step 1:** Points to the drug selection dropdown menu in the IVIg section.
- Step 2:** Points to the dose input field and its unit label in the IVIg section.
- Step 3:** Points to the date availability dropdown in the IVIg section.
- Step 4:** Points to the date input field in the IVIg section.
- Step 5:** Points to the course length input field and its unit label in the Prednisolone section.
- Step 6:** Points to the completion status dropdown at the bottom of the form.

The form includes fields for 'Is the treatment date available?', 'Full Treatment date', 'ITP Treatment', 'IVIg dose', 'Is the start treatment date available?', 'Full treatment date', 'How long (duration) was this drug prescribed for?', and 'Form Status'. It also has buttons for 'Save & Exit Form' and '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	<input type="text" value="Platelets"/>
Platelets dose	<input type="text"/>
	units
Is the start treatment date available?	<input type="text"/>
How long (duration) was this prescribed for?	<input type="text"/>
	Please state in DAYS. A course duration is the length of time that the transfusion was given over
Blood Transfusion Type	<input type="text"/>
Form Status	<input type="text"/>
Complete?	<input type="text"/>
Lock this record for this form?	<input type="text"/>
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:** 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

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.

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

**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**

**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 -- 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

Save & Exit Form

Save & Go To Next Form

-- Cancel --

Name of Anti-hypertensive therapy

Indoramin

Course

Continuous

Start Date Status

complete date available

Full Start Date

01-12-2015 Today D-M-Y

End Date Status

complete date available

Full End Date

01-12-2017 Today D-M-Y

**CO-THERAPIES**

**Cotherapies**

Anti-lipid therapy

Anti-lipid therapy

Antihypertensive therapy

Anti-coagulant therapy

Thrombolysis therapy

Anti-fibrinolytic therapy

Name of Anti-lipid therapy

Course

Start Date Status

End Date Status

**CO-THERAPIES**

**Cotherapies**

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.

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

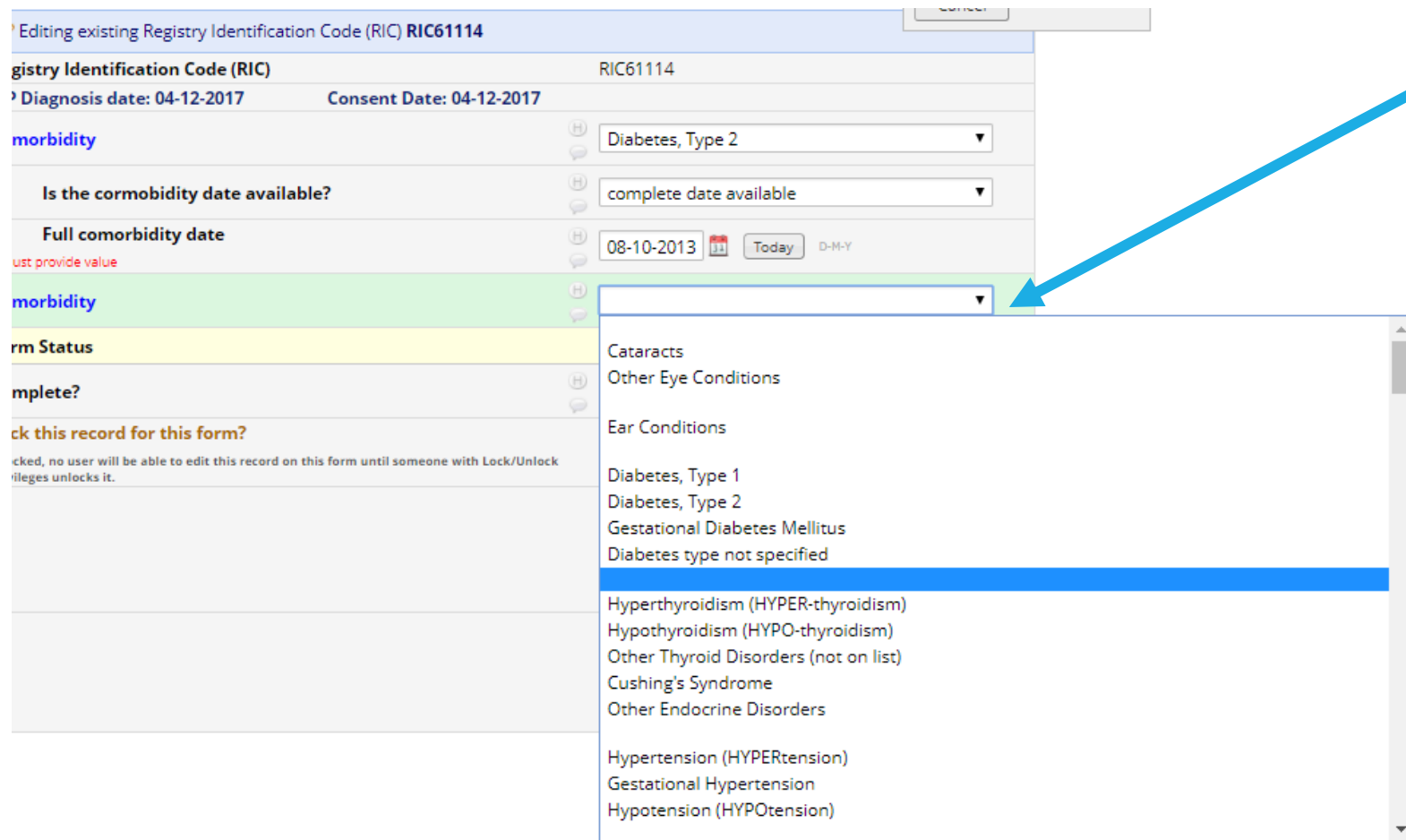
**Step 3:** Enter whether the course was continuous, a one-off or whether it is unknown which of these it was.

**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). The form is titled "Editing existing Registry Identification Code (RIC) RIC61114". It contains several sections: "Registry Identification Code (RIC)" with the value "RIC61114", "Diagnosis date: 04-12-2017" and "Consent Date: 04-12-2017", a "comorbidity" section with a dropdown menu showing "Diabetes, Type 2", a section "Is the comorbidity date available?" with a dropdown menu showing "complete date available", and a "Full comorbidity date" section with a date picker showing "08-10-2013". A red text "must provide value" is visible below the date picker. A dropdown menu is open, showing a list of co-morbidities: Cataracts, Other Eye Conditions, Ear Conditions, Diabetes, Type 1, Diabetes, Type 2, Gestational Diabetes Mellitus, Diabetes type not specified, Hyperthyroidism (HYPER-thyroidism), Hypothyroidism (HYPO-thyroidism), Other Thyroid Disorders (not on list), Cushing's Syndrome, Other Endocrine Disorders, Hypertension (HYPERtension), Gestational Hypertension, and Hypotension (HYPOtension). A blue arrow points from the "Step 1" instruction to the dropdown menu.

Editing existing Registry Identification Code (RIC) RIC61114

Registry Identification Code (RIC) RIC61114

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

comorbidity Diabetes, Type 2

Is the comorbidity date available? complete date available

Full comorbidity date 08-10-2013 Today D-M-Y

must provide value

comorbidity

Form Status

Complete?

Lock this record for this form?

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

- Cataracts
- Other Eye Conditions
- Ear Conditions
- Diabetes, Type 1
- Diabetes, Type 2
- Gestational Diabetes Mellitus
- Diabetes type not specified
- Hyperthyroidism (HYPER-thyroidism)
- Hypothyroidism (HYPO-thyroidism)
- Other Thyroid Disorders (not on list)
- Cushing's Syndrome
- Other Endocrine Disorders
- Hypertension (HYPERtension)
- Gestational Hypertension
- Hypotension (HYPOtension)

**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

Registry Identification Code (RIC) RIC61114

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

Does the participant have any of the following?

Family history of cancer

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

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?**

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

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

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)**

reference range:  
Male: 13.0 - 18.0 g/dL  
Female: 11.5 - 16.5 g/dL

Is the date available?

**Neutrophils Count (Level at Diagnosis) ( $\times 10^9/L$ )**

reference range: **1.8 - 7.5**

Is the date available?

**White Blood Cells Count (Level at Diagnosis) ( $\times 10^9/L$ )**

reference range: **4 - 11**

Is the date available?

**Red Blood Cells Count (Level at Diagnosis) ( $\times 10^{12}/L$ )**

reference range:  
Male: 3.97 - 5.54 /pL  
Female: 3.66 - 4.9 /pL

Is the date available?

**Mean Platelet Volume (MPV) [Volume at Diagnosis]**

Count

Is the date available?

**Blood Group**

☐ O  
☐ AB  
☐ A  
☐ B  
☐ Unknown/Untested

reset

Is the date available?

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**   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=  $\times 10^9/l$ )

**Step 2:** Select whether the date is available

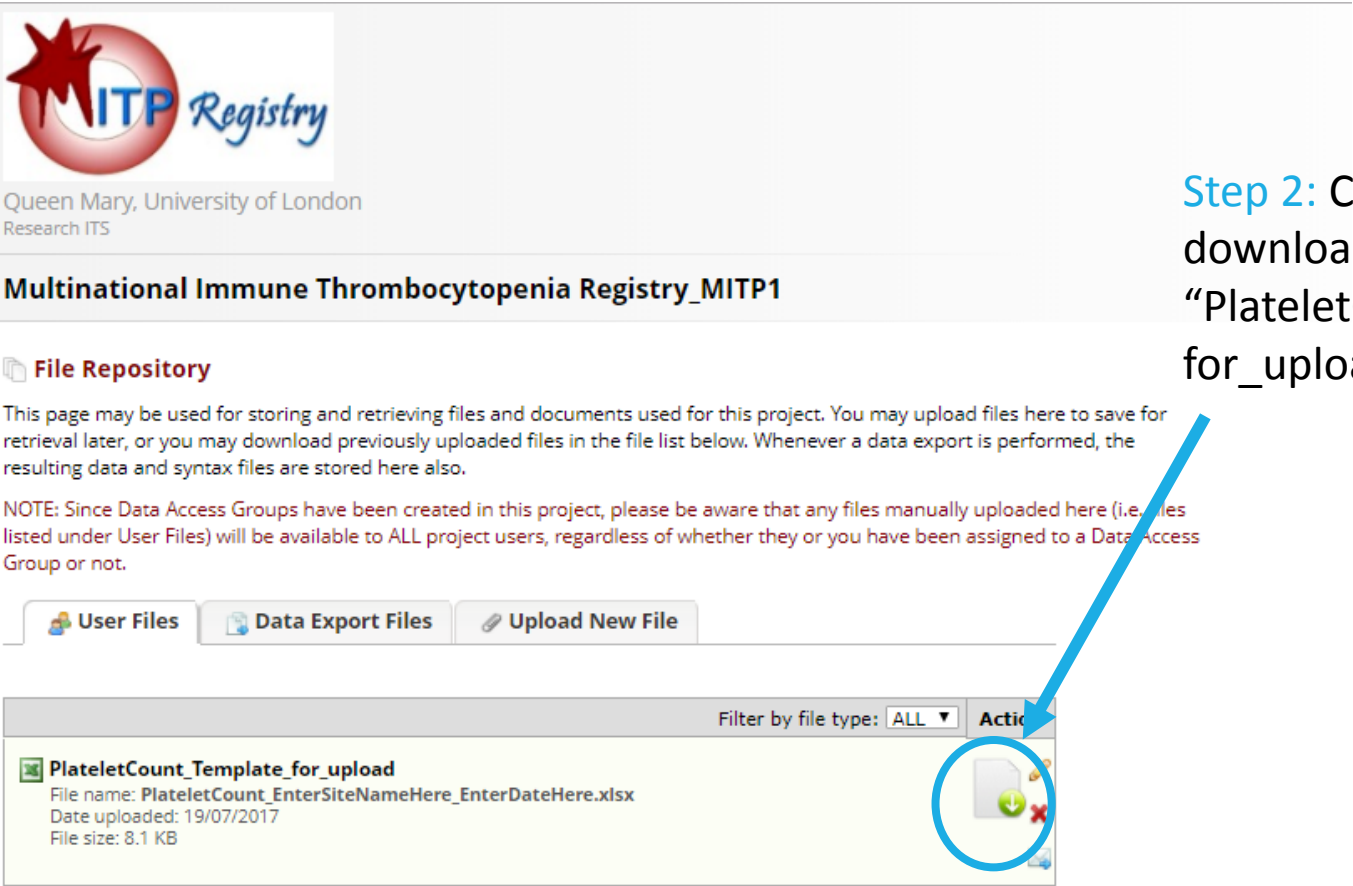
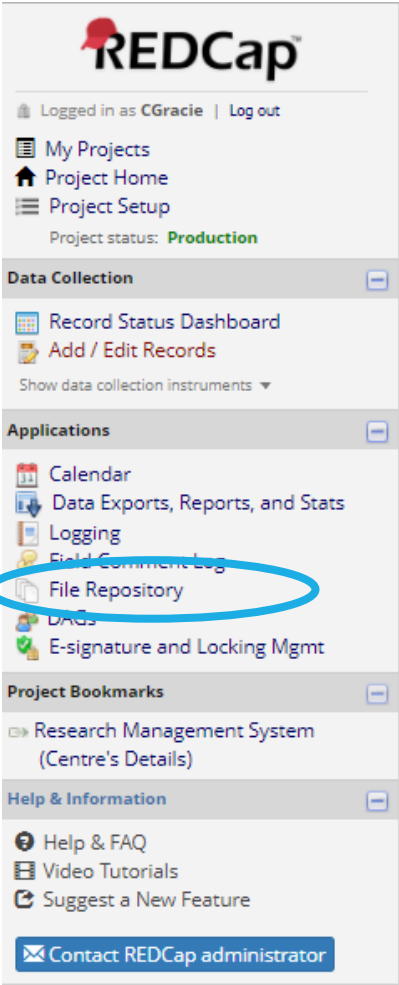
**Step 3:** Enter the date

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



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

RIC in every row



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

	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						

Date the platelet count was measured as short date format





# Platelet Counts File Upload Function: uploading template

Step 5: Click on  
“Platelet Counts File  
Upload Function”

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](#)
- Data Collection Instruments:
  - Participant Details
  - Follow Up Data Collection Status Update
  - Clinician Information
  - Anthropometric And Lifestyle Data
  - Bleeding Events
  - Itp Treatments
  - Blood Product Transfusion
  - Other Itp Treatments
  - Trial
  - Cotherapies
  - Comorbidities
  - Family History
  - Biochemical Fields At Itp Diagnosis
  - Haematological Fields At Itp Diagnosis
  - Platelet Counts Manual Entry
  - Platelet Counts File Upload Function**
  - Immunological Fields At Itp Diagnosis
  - Coagulation Fields At Itp Diagnosis
  - Bm Aspirate Trepnine Binovs Dat

## Multinational Immune Thrombocytopenia Registry\_test 4

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

### Platelet Counts File Upload Function

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

#### 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 ==>

\* must provide value

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 attach  
The excel sheet can be used to load all the plate  
Save the excel sheet in folder where you can loc  
Click on 'Upload Document'  
Find the excel sheet under browse and select it  
'upload document'  
Do not forget to save page when finished  
and  
send a copy of this excel sheet with the platelet  
uk-ityp.registryteam@nhs.net  
with subject title in the email: Platelet Count Up

Upload document

### Upload document

Please upload platelet counts here ==> (platelet\_upload\_done)

Select a file then click the 'Upload Document' button

Choose File PlateletCoun...ec2017.xlsx

Upload document (Max file size: 32 MB)

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 ==>

\* must provide value

[PlateletCount ABC12345 01Dec2017... \(0.01 MB\)](#)

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](#)

[Save & Exit Form](#)  
[Save & Go To Next Form](#)  
[-- Cancel --](#)

**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?

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](#)

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

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

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?

☒ Yes  
☐ No  
☐ Uncertain

Bone Marrow Aspirate

Is the date available?

Marrow Aspirate Conclusion

Trephine Biopsy

Is the date available?

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

**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**

ⓘ  
💬

other comments
Expand

**Other Comments**

ⓘ  
💬

other comments
Expand

**Other Comments**

ⓘ  
💬

other comments
Expand

**Other Comments**

ⓘ  
💬

other comments
Expand

**Other Comments**

ⓘ  
💬

other comments
Expand

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 links, a main content area with a status message and a table of data collection instruments, and a legend for status icons.

**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.

**Legend for status icons:**

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

Registry Identification Code (RIC) **RIC61114** successfully edited

Registry Identification Code (RIC) **RIC61114**

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
Cootherapies	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 Trephine 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](mailto:uk-itp.registryteam@nhs.net)  
or call 02073 777 000 ext 61114 9am-5pm, Mon-Fri