

UKITP Pregnancy Registry Data Entry Guide

**Terms and Conditions of Using REDCap &
Self-Help Visual Guide**



Welcome to the ITP Pregnancy Registry

Thank you for supporting and being part of the UK ITP registry. The registry aims to better understand the causes, treatment responses and outcomes in patients with primary ITP. The ITP registry has now been extended to include ongoing, prospective data collection regarding the management and outcome of pregnancy in patients with ITP. This is to further our understanding of the epidemiology of ITP in pregnancy, pregnancy outcomes and provide a prospective tool to guide evidence based consistent practise.

Dr Susan Robinson (Guy's & St Thomas' NHS Foundation Trust) is the Co-Investigator for the pregnancy section of the UKITP Registry.

All data collected for the UK ITP adult registry and pregnancy registry will be entered onto our online database, the database we use is called REDCap (© 2022 Vanderbilt University) Version 7.4.20 - <https://redcap.qmul.ac.uk/>.

The present user guide aims to help you understand how to enter participants data for the pregnancy section of the registry onto REDCap.



Terms and Conditions of Using REDCap

Prior to providing your credentials for REDCap, you are required to accept the general terms and conditions of using REDCap, in addition to these, you must also be aware that:

Data Collection

- Only data belonging to participants who have consented and are eligible to participate in the pregnancy registry should be entered onto the database (i.e. a valid signed consent form has been obtained).

NB: All documents and designs that the UKITP Registry uses are copyrighted.



Terms and Conditions of Using REDCap

In line with data protection regulations, sites using the ITP registry database **must** ensure the following:

- Only staff who are on the delegation log and assigned the 'data entry' role (signed by the local Principal Investigator) can have access to the database.
- 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 onto REDCap.



REDCap Self-Help Visual Guide for Data Entry

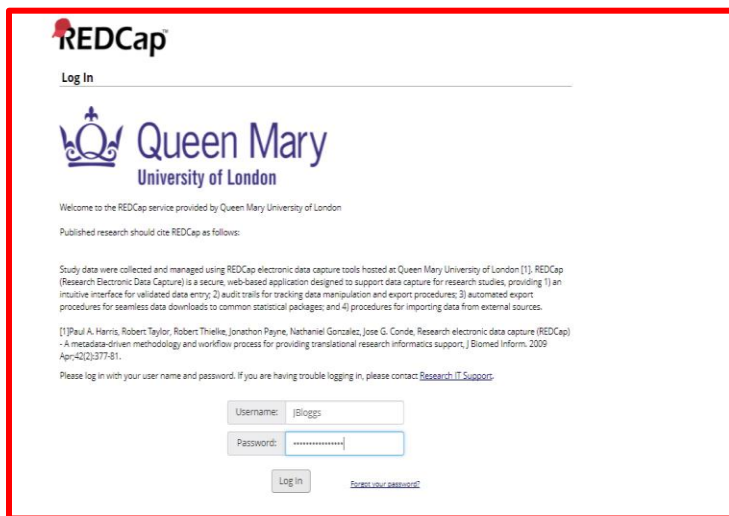


Logging into REDCap and Entering the UKITPR

You can access the ITP registry database by logging into REDCap using the following link –

<https://redcap.qmul.ac.uk/>

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



The image shows the REDCap login page for Queen Mary University of London. It includes the REDCap logo, the university name, and a 'Log In' button. Below the login button, there is a 'Forgot your password?' link. The page also contains a welcome message and a list of published research projects.

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

Project Title	Records	Fields	Instrument	Type	Status
Research Management System_MITP1	14	301	4 forms		✓
The UK ITP Registry	3,128	470	39 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)
Multiple Surveys (longitudinal)
Piping Example Project

Step 2: You should have two projects under 'My Projects':

1. Research Management System_MITP: this is the staff details database for your site.
2. The UK ITP Registry: this is where you can enter patient data, please select this project.

Step 3: You have now entered the UKITPR project, please select 'Add / Edit Records' to add a new patient or edit the data of an existing patient.



Step 4: You must select 'Arm 2: Pregnancy Registry' listed on both drop-down lists.

What is an RIC?



When a new patient joins the registry, their details must be recorded on the 'Participants Log', each patient entered on the log is assigned a unique RIC (e.g. ABC123).

You may view an existing record/response by selecting it from the drop-down lists below. To create a new record/response, enter 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 below will populate with existing record names as you begin to type in it, allowing you to select it.

Step 5: Then manually enter the Registry Identification Code (RIC) of the record you wish to view.

REDCap

Logged in as amiah | Log out

My Projects

Project Home

Project Setup

Project status: Development

Data Collection / [Edit instruments](#)

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)

ABC123 [Select other record](#)

Applications

Calendar

Data Exports, Reports, and Stats

Data Import Tool

Data Comparison Tool

Logging

Field Comment Log

File Repository

User Rights and DAGs

E-signature and Locking Mgmt

Data Quality

Reports / [Edit reports](#)

1) Rx Details

Help & Information

Help & FAQ

Video Tutorials

Suggest a New Feature

[Contact REDCap administrator](#)

The UK ITP Registry

Record Home Page

Record "ABC123" is a new Registry Identification Code (RIC). To create the record and begin entering data for it, click any gray status icon below.

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. If you wish, you may modify the events below by navigating to the [Define My Events](#) page.

Legend for status icons:

- Incomplete
- Incomplete (no data saved) ?
- Unverified
- Many statuses (all same)
- Complete
- Many statuses (mixed)

NOTICE: Please note that Registry Identification Code (RIC) "ABC123" also exists on another arm.

NEW Registry Identification Code (RIC) ABC123

Arm 2: Pregnancy Registry

[+ Add new](#)

2nd and Subsequent Pregnancies

Data Collection Instrument	First Registered Pregnancy	2nd and Subsequent Pregnancies
Pregnancy Registration Details		
Clinician Information		
Obstetric History		
Problems In Previous Pregnancies		
Morbid Events In Previous Pregnancies		
Current Pregnancy Information		
Anthropometric and Lifestyle Information		
Bleeding Events During Pregnancy		
ITP Treatments During Pregnancy		
Supportive Therapies During Pregnancy		
Anaesthesia Method At Delivery		
Haematological Values During Pregnancy		
Coagulation Results At Delivery		
Details Of Delivery		
Maternal Outcome		
Comorbid Conditions During Pregnancy Or Up To 3 Months		
Infant Details		
Infant Morbidity		
Infant Platelet Counts		
Infant Thrombocytopenia Treatments		
Breast Feeding		

Repeating Instruments

Date of Follow Ups

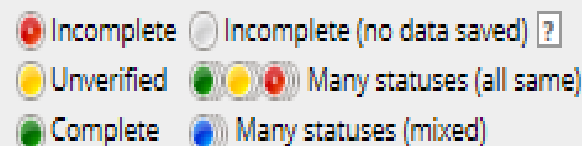
UK ITP Registry (Arm 1: UK ITP Registry)

1	
2	

[+ Add new](#)

Step 6: You should now be on the 'Record Home Page' which lists all the forms for pregnancy registry. Click on the relevant status circle of the form you would like to complete. If this is not the first pregnancy entered on the registry, please use the forms listed under '2nd and Subsequent Pregnancies'. If you would like to add a third pregnancy, select "Add New".

Legend for status icons:



REDCap uses a traffic light system to record whether each form is complete. You control this system by marking forms as complete, incomplete or unverified at the end of each form - this system is for you to track your own progress.

Data Collection Forms

You may use the 'UKITPR Pregnancy Registration Sheet 2.0' and 'UKITPR Pregnancy Status and Outcome Sheet 2.0' to aid your data entry.

Pregnancy Registration Details

The UK ITP Registry

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

Pregnancy Registration Details

Data Access Group: [No Assignment] ?

Editing existing Registry Identification Code (RIC) **ABC123**

Event Name: **First Registered Pregnancy (Arm 2: Pregnancy Registry)**

Registry Identification Code (RIC) **ABC123**

UK Immune Thrombocytopenia Pregnancy Registry Dr Susan Robinson, Guy's & St Thomas' NHS Foundation Trust, is the Co-Investigator for the Pregnancy section of the UKITP Registry. Please contact the ITP registry team at uk-itp.registryteam@nhs.net for any queries regarding the pregnancy database.

Registry Identification Code (RIC): **ABC123**

ITP Diagnosis date: **24-08-2018**

Registration date: **24-08-2018**

Ethnicity: **White- English/Welsh/Scottish/Northern Irish/British**

If any of the above are blank, please fill out this information in the main section of the UK ITP Registry

Please re-enter the DOB for record validation purposes: Today D-M-Y

Consent Date for Pregnancy Registry Today D-M-Y

Estimated Delivery Date Today D-M-Y

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 & ...](#)

[-- Cancel --](#)

Information Merged from Adult Registry:

As all participants registering for the pregnancy registry will already be part of the adult registry, some basic details are merged over.

To ensure that the adult registry record matches the pregnancy registry record, you are required to re-enter the participants DOB. You can enter this by clicking on the calendar icon or manually typing the numbers – this also applies for the following questions.

[Save & Exit Form](#) [Save & ...](#)

[-- Cancel --](#)

[Save & Stay](#)

[Save & Go To Next Form](#)

This question allows you to control the traffic light system to record whether each form is complete, if you select complete the status icon will turn green - (complete=green, unverified=yellow, incomplete=red).

To go to the next form, select 'Save & Go To Next Form', to exit select 'Save & Exit Form'.

Clinician Information

Clinician Information Data Access Group: [No Assignment] ?

Editing existing Registry Identification Code (RIC) **ABC123**

Event Name: **First Registered Pregnancy (Arm 2: Pregnancy Registry)**

Registry Identification Code (RIC) **ABC123**

Haematologist's Details

Haematologist's Name

Hospital/Centre Name

City/Town

Obstetrician's Details

Obstetrician's Name

Hospital/Centre Name

City/Town

Maternity Unit's Details

Maternity Unit

Hospital/Centre Name

City/Town

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 & ...**

Enter the participant's Haematologist, Obstetrician and Maternity Unit details using the free-text boxes available.

Assign completion status and click on "Save & Go To The Next Form" – you must do this for ALL forms.

Please do not lock forms as it will prevent you and any of your colleagues from editing the record.

Obstetric History

Obstetric History

Data Access Group: [No Assignment] ?

Editing existing Registry Identification Code (RIC) ABC123

Event Name: **First Registered Pregnancy (Arm 2: Pregnancy Registry)**

Registry Identification Code (RIC) ABC123

The information below is necessary if this is the first pregnancy registered on the Pregnancy Registry.

Is this the first pregnancy registered on the Pregnancy Registry? ☒ Yes ☐ No

Number of previous pregnancies beyond 24 weeks gestation

Number of previous pregnancies less than 24 weeks gestation

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.

Exit Form Save & ...

Delete data for THIS FORM only

Please select the relevant option.

Using the drop-down boxes available, select the number of previous pregnancies beyond 24 weeks gestation and number of pregnancies less than 24 weeks gestation.

Problems in Previous Pregnancy

Problems in Previous Pregnancies

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

Editing existing Registry Identification Code (RIC) ABC123

Event Name: First Registered Pregnancy (Arm 2: Pregnancy Registry)

Registry Identification Code (RIC) ABC123

Did the participant experience any of the following problems in previous pregnancies?

- 3 or more miscarriages up to 12 weeks gestation
- Mid trimester loss 12-24 weeks gestation
- Late pregnancy loss after 24 weeks gestation
- Baby with Congenital anomaly
- Eclampsia
- Gestational diabetes
- Infant requiring admission to the neonatal unit
- Infection requiring hospital admission
- Massive Haemorrhage
- Neonatal death
- Placenta Praevia
- Placental abruption
- Post-partum haemorrhage requiring transfusion
- Preeclampsia
- Preterm birth (between 24-37 weeks gestation)
- Still birth
- Surgical procedure in pregnancy
- Other (please specify)

To add another problem, please click on 'Save and go to next instance' in the blue box on the bottom right of this page. Click on the little arrow to find this option if the box says 'save and go to next form'.

Previous problems in pregnancy

Date Today D-M-Y

Is only part of the date available? Yes No

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 & ...

Using the drop-down box available, select any problems the patient has experienced during previous pregnancies.

Save & Exit Form Save & ...

-- Cancel --

Delete data for THIS Form

Save & Stay

Save & Add New Instance

Save & Go To Next Form

To add another problem, please click on 'Save And Go To Next Instance' in the blue box on the bottom right of this page - click on the little arrow to find this option. This will present you with a duplicate form to enter the additional data.

Morbid Events in Previous Pregnancies

Morbid Events In Previous Pregnancies

Data Access Group: [No]

Save & Exit Form

Save & Add New Instance

-- Cancel --

Editing existing Registry Identification Code (RIC) **ABC123**

Event Name: **First Registered Pregnancy (Arm 2: Pregnancy Registry)**

Registry Identification Code (RIC) **ABC123**

Did the participant experience any of the following morbid event during pregnancies?

- Adult Respiratory Distress Syndrome
- Cardiac Arrest
- Disseminated Intravascular Coagulation
- Haemolysis, elevated liver function, low platelets (HELLP)
- Required mechanical ventilator support
- Septicaemia
- Other (please specify)

To add another morbid event, please click on 'Save and go to next instance' in the blue box on the bottom right of this page. Click on the little arrow to find this option if the box says 'save and go to next form'.

Morbid events experienced in previous pregnancies

Date

Is only part of the date available?

Form Status

Complete?

Lock this record for this form?

Save & Exit Form

Save & Add New Instance

Using the drop-down box available, select any morbid events the patient has experienced during previous pregnancies. As mentioned for the previous form, additional morbid events can be added by selecting the 'Save & Add New Instances' option.

Morbid Events In Previous Pregnancies

Current instance: 1 / 2

Editing existing Registry Identification Code (RIC) **ABC123**

Event Name: **First Registered Pregnancy (Arm 2: Pregnancy Registry)**

Registry Identification Code (RIC) **ABC123**

1 / 2

2 / 2

+ Add new

Once a new instance has been added, a small tab will appear on your screen, this tab outlines the number of instances you have recorded for this specific form.

Current Pregnancy Information

Current Pregnancy Information

Data Access Group: [No Assignment] ?

Editing existing Registry Identification Code (RIC) ABC123

Event Name: First Registered Pregnancy (Arm 2: Pregnancy Registry)

Registry Identification Code (RIC) ABC123

Details on Current Pregnancy

1st date of last menstrual period Today D-M-Y

Final estimated date of delivery Today D-M-Y

Is this a multiple pregnancy? ☐ Yes ☐ No

Was ITP diagnosed in this pregnancy? ☐ Yes ☐ No

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 & Stay -- Cancel --

You can enter the date by clicking on the calendar icon or manually typing the numbers – this also applies for the following questions.

Please select the relevant option.

Is this a multiple pregnancy? ☒ Yes ☐ No

Number of fetuses

Was ITP diagnosed in this pregnancy? ☐ Yes ☐ No

ITP Diagnosis Date Today D-M-Y

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 note that some questions contain branching logic – this means that a specific answer to a question triggers another question to gather more insight.

Anthropometric and Lifestyle Information

Anthropometric and Lifestyle Information

Data Access Group: [No Assignment] ?

Editing existing Registry Identification Code (RIC) ABC123

Event Name: First Registered Pregnancy (Arm 2: Pregnancy Registry)

Registry Identification Code (RIC) ABC123

Please enter the following lifestyle information. This section only needs to be done once when the participant is registered.

Participant booking weight (kg) kg

Date Today D-M-Y

Smoking

Smoking status Never
Gave up before pregnancy
Gave up during pregnancy
Current
No data

Alcohol Consumption

Alcohol consumption before pregnancy Today D-M-Y

Alcohol consumption during pregnancy Today D-M-Y

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 & Stay

-- Cancel --

Enter participants weight in kg using the free text box available.

Using the drop-down boxes available, select the relevant answers to the questions regarding smoking and alcohol status.

Reminder: Assign completion status and click on “Save & Go To The Next Form” – you must do this for ALL forms.

Bleeding Events During Pregnancy

The UK ITP Registry

Actions: [Modify instrument](#) [Download PDF of instrument\(s\)](#) [VIDEO: Basic data entry](#) [Save & Exit Form](#) [Save & Add New Instance](#) [Cancel](#)

Bleeding Events During Pregnancy

Data Access Group: [No Assignment] ?

Editing existing Registry Identification Code (RIC) ABC123

Event Name: First Registered Pregnancy (Arm 2: Pregnancy Registry)

Registry Identification Code (RIC) ABC123

Please enter any bleed events that occurred during pregnancy.

To add another bleed event, please click on 'Save and go to next instance' in the blue box on the right hand side at the bottom of the page. You may have to click on the little arrow to find this option if the box says 'save and go to next form'.

Skin

Bleed Type/Site

Bruise Severity

Date of Bleed

Is only part of the date available? ☐ Yes ☐ No

Mucosal

Bleed Type/Site

Date of Bleed

Is only part of the date available? ☐ Yes ☐ No

Organ

Bleed Site

Date of Bleed

Is only part of the date available? ☐ Yes ☐ No

Other

Bleed Type

Date of Bleed

Is only part of the date available? ☐ Yes ☐ No

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 & Add New Instance](#)

Using the drop-down boxes available, select the bleeding events that have occurred and date of the bleeds. As mentioned for some of the previous forms, additional bleeding events can be added by selecting the 'Save & Add New Instances' option.

Mucosal

Bleed Type/Site

Epistaxis Severity

Was a transfusion required? ☐ Yes ☐ No

Date of Bleed

Is only part of the date available? ☐ Yes ☐ No

Most of the questions regarding bleeding events contain branching logic to gather information on the severity of the bleed and to find out whether transfusion was required.

ITP Treatments During Pregnancy

ITP Treatments During Pregnancy

Data Access Group: [No Assignment] ?

Editing existing Registry Identification Code (RIC) **ABC123**

Event Name: **First Registered Pregnancy (Arm 2: Pregnancy Registry)**

Registry Identification Code (RIC) **ABC123**

Please enter any ITP Treatments that were given during pregnancy.

To add another treatment, please click on 'Save and go to next instance' in the blue box on the right hand side at the bottom of the page. You may have to click on the little arrow to find this option if the box says 'save and go to next form'.

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 & Add New Instance

Select 'Save & Add New Instances' to enter another treatment.

Once a treatment has been selected, you will be prompted to answer questions about the indication to treat (answer via drop-down list), dose (free-text), dose unit (drop-down list) and start/end dates.

Treatment

Indication to Treat

Unit of Dose

Dose

Start Date

Supportive Therapies During Pregnancy

Supportive Therapies During Pregnancy

Data Access Group: [No Assignment] ?

Editing existing Registry Identification Code (RIC) **ABC123**

Event Name: **First Registered Pregnancy (Arm 2: Pregnancy Registry)**

Registry Identification Code (RIC) ABC123

Please enter Supportive Therapies used during Pregnancy.

Treatment

No. of units prescribed per day

Start Date D-M-Y

Is only part of the date available? ☐ Yes ☐ No

End Date D-M-Y

Is only part of the date available? ☐ Yes ☐ No

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 & Add New Instance** **-- Cancel --**

Using the drop-down list, select a therapy then enter the units prescribed per day using the free text box that appears. The start/end dates are also required.

Anaesthesia Method at Delivery

Anaesthesia Method At Delivery

Data Access Group: [No Assignment] ?

Editing existing Registry Identification Code (RIC) **ABC123**

Event Name: **First Registered Pregnancy (Arm 2: Pregnancy Registry)**

Registry Identification Code (RIC) ABC123

Please enter Anaesthesia Method at Delivery.

Did the patient receive regional anaesthesia during delivery? ☒ Yes ☐ No [reset](#)

Date received [Today](#) D-M-Y

Was regional anaesthesia withheld due to the platelet count or coagulation laboratory results at the time of delivery? ☒ Yes ☐ No [reset](#)

Form Status

Complete? [reset](#)

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 & Stay](#) [-- Cancel --](#)

You must record whether the patient received regional anaesthesia during delivery. If yes, you will need to record the date.

Reminder: Assign completion status and click on “Save & Go To The Next Form” – you must do this for ALL forms.

Haematological Values During Pregnancy

Haematological Values During Pregnancy

Data Access Group: [No Assignment] ?

Editing existing Registry Identification Code (RIC) **ABC123**

Event Name: **First Registered Pregnancy (Arm 2: Pregnancy Registry)**

Registry Identification Code (RIC) ABC123

Blood results during pregnancy and up to 3 months afterwards.

Earliest FBC available in pregnancy

Platelet	<input type="text"/>
Hb	<input type="text"/>
WBC	<input type="text"/>
Neutrophil	<input type="text"/>
RBC	<input type="text"/>
MPV	<input type="text"/>
Date	<input type="text"/> Today D-M-Y

FBC with lowest platelet count during pregnancy

Platelet	<input type="text"/>
Hb	<input type="text"/>
WBC	<input type="text"/>
Neutrophil	<input type="text"/>
RBC	<input type="text"/>

Using the free-text boxes available under each sub-heading, please enter the Full Blood Count (FBC) available during pregnancy, FBC with lowest platelet count during pregnancy, FBC at delivery and FBC 3 months post-partum (along with the corresponding dates).

Coagulation Results at Delivery

Coagulation Results At Delivery

Data Access Group: [No]

Save & Exit Form

Save & Stay

-- Cancel --

Editing existing Registry Identification Code (RIC) **ABC123**

Event Name: **First Registered Pregnancy (Arm 2: Pregnancy Registry)**

Registry Identification Code (RIC) **ABC123**

Please give coagulation values from time of delivery.

Prothrombin Time (PT)

INR (if Prothrombin Time (PT) not available)

Activated partial thromboplastin time (APTT)

Activated partial thromboplastin ratio (if APTT time not available)

Fibrinogen

Date of results

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 & Stay

-- Cancel --

Following on from the previous form, please use this page to report the coagulation results at delivery using the free-text options available.

Reminder: Assign completion status and click on “Save & Go To The Next Form” – you must do this for ALL forms.

Details of Delivery

Details Of Delivery

Data Access Group: [No]

Editing existing Registry Identification Code (RIC) ABC123

Event Name: First Registered Pregnancy (Arm 2: Pregnancy Registry)

Registry Identification Code (RIC) ABC123

Details of Delivery

Did this woman have a miscarriage? ☐ Yes ☐ No

Did this woman have a termination of pregnancy? ☐ Yes ☐ No

Was delivery induced? ☐ Yes ☐ No

Did the woman labour? ☐ Yes ☐ No

Type of Delivery

Vaginal ☐ Yes ☐ No

Caesarean section ☐ Yes ☐ No

Were Ventouse forceps used? ☐ Yes ☐ No

Were Lift out Forceps used? ☐ Yes ☐ No

Were Rotational Forceps used? ☐ Yes ☐ No

Was it a breech delivery? ☐ Yes ☐ No

What was the estimated blood loss during labour/caesarean section? (ml)

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 & Stay

Please select the relevant option for each section.

Caesarean section ☒ Yes ☐ No

Date of C-section Today D-M-Y

Indication for Caesarean section

Grade of urgency for Caesarean section

Please note that some questions contain branching logic – this means that a specific answer to a question triggers another question to appear to gather more insight. When answering ‘Yes’ to any of these questions, you will be prompted to provide the date. The question on Caesarean section (as shown above), will ask for more information such as indication and grade for caesarean - these should be answered via the drop-down lists available.

Maternal Outcome

Maternal Outcome

Data Access Group: [No]

Editing existing Registry Identification Code (RIC) ABC123

Event Name: First Registered Pregnancy (Arm 2: Pregnancy Registry)

Registry Identification Code (RIC) ABC123

Please enter details regarding Maternal Outcome below.

Did the participant have a Caesarean section wound haematoma? ☐ Yes ☐ No [reset](#)

Date Today D-M-Y

Did the participant have a neuroaxial anaesthesia haematoma? ☐ Yes ☒ No [reset](#)

Did the participant have a perineal haematoma? ☐ Yes ☒ No [reset](#)

Did the participant have a post-partum haemorrhage? ☐ Yes ☒ No [reset](#)

Was a transfusion of red blood cells required? ☐ Yes ☒ No [reset](#)

Form Status

Complete? [reset](#)

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 & Stay](#)

Please select the relevant option for each question and report the date using the calendar icon or manually typing the numbers.

Comorbid Conditions During Pregnancy or 3 Months Post-Partum

Comorbid Conditions During Pregnancy Or Up To 3 Months

Data Access Group: [No]

Editing existing Registry Identification Code (RIC) **ABC123**

Save & Exit Form

Save & Add New Instance

-- Cancel --

Event Name: **First Registered Pregnancy (Arm 2: Pregnancy Registry)**

Registry Identification Code (RIC) ABC123

Please enter any co-morbid conditions during Pregnancy or 3 months post-partum below.

To add another co-morbid condition, please click on 'Save and go to next instance' in the blue box on the right hand side at the bottom of the page. You may have to click on the little arrow to find this option if the box says 'save and go to next form'.

Did the participant have any major maternal morbidity?

Date Today D-M-Y

Did the participant die? ☐ Yes ☒ No

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 & Add New Instance

Using the drop-down box available, select any comorbid conditions the participant has experienced during pregnancy or 3 months post-partum.

You can add additional comorbid conditions by selecting the 'Save & Add New Instances' option.

Infant Details

Infant Details Data Access Group: Royal London Hospital ?

Editing existing Registry Identification Code (RIC) **test123**

Event Name: **First Registered Pregnancy (Arm 2: Pregnancy Registry)**

Registry Identification Code (RIC) **test123**

Please enter infant details below.

Did the patient give birth to more than 1 baby? ☒ Yes ☐ No reset

How many babies did the patient give birth to? reset

Date of Birth D-M-Y

Time of Birth

Birth weight (g) grams

Was the infant stillborn? ☐ Yes ☐ No reset

Was the infant admitted to the neonatal unit? ☐ Yes ☐ No reset

Date of Birth (Infant 2) D-M-Y

Time of Birth (Infant 2)

Birth weight (g) (Infant 2) grams

Was the infant stillborn? (Infant 2) ☐ Yes ☐ No reset

Was the infant admitted to the neonatal unit? (Infant 2) ☐ Yes ☐ No reset

Please specify if multiples babies were delivered.

Select the number of babies (up to 4).

Selecting the correct number of babies ensures that questions relating to each infant becomes automatically available on this form and all subsequent forms.

Infant Details Continued

Infant Details

Data Access Group: [No]

Editing existing Registry Identification Code (RIC) **ABC123**

Event Name: **First Registered Pregnancy (Arm 2: Pregnancy Registry)**

Registry Identification Code (RIC) ABC123

Please enter infant details below.

Date of Birth 29-08-2018 Today D-M-Y

Birth weight (g) 2721 grams

Was the infant stillborn? ☐ Yes ☒ No reset

Was the infant admitted to the neonatal unit? ☒ Yes ☐ No reset

Date 29-09-2018 Today D-M-Y

Form Status

Complete? 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.

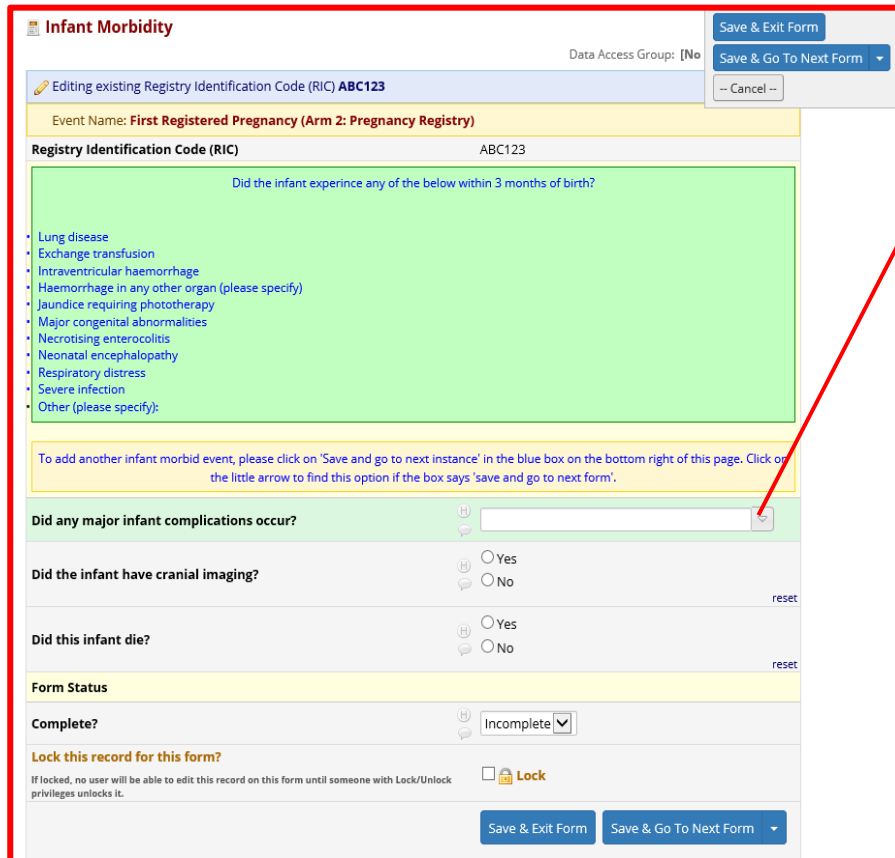
Save & Exit Form Save & Go To Next Form Cancel

Please enter infant details on this form.

Enter weight in grams.

Reminder: Assign completion status and click on "Save & Go To The Next Form" – you must do this for ALL forms.

Infant Morbidity



Infant Morbidity

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

Editing existing Registry Identification Code (RIC) ABC123

Event Name: First Registered Pregnancy (Arm 2: Pregnancy Registry)

Registry Identification Code (RIC) ABC123

Did the infant experience any of the below within 3 months of birth?

- Lung disease
- Exchange transfusion
- Intraventricular haemorrhage
- Haemorrhage in any other organ (please specify)
- Jaundice requiring phototherapy
- Major congenital abnormalities
- Necrotising enterocolitis
- Neonatal encephalopathy
- Respiratory distress
- Severe infection
- Other (please specify):

To add another infant morbid event, please click on 'Save and go to next instance' in the blue box on the bottom right of this page. Click on the little arrow to find this option if the box says 'save and go to next form'.

Did any major infant complications occur?

Did the infant have cranial imaging? ☐ Yes ☐ No

Did this infant die? ☐ Yes ☐ No

Form Status

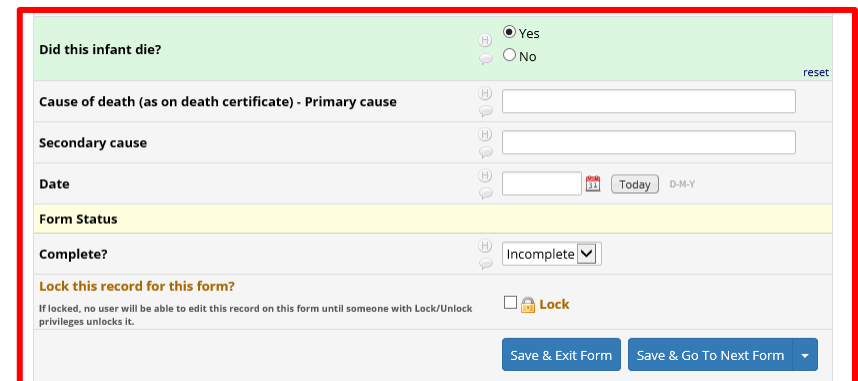
Complete?

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

Using the drop-down box available, select any infant morbidities that have occurred. You can add additional morbidities by selecting the 'Save & Add New Instances' option.



Did this infant die? ☒ Yes ☐ No

Cause of death (as on death certificate) - Primary cause

Secondary cause

Date Today D-M-Y

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

Some of the questions listed contain branching logic – as mentioned previously, this means that a specific answer to a question (e.g. regarding infant death) triggers another question to appear to gather more insight.

Infant Platelet Counts

Infant Platelet Counts

Data Access Group: [No Assignment] ?

Editing existing Registry Identification Code (RIC) **ABC123**

Event Name: **First Registered Pregnancy (Arm 2: Pregnancy Registry)**

Registry Identification Code (RIC) ABC123

Please enter Infant Platelet Counts below.

Is a delivery cord or neonatal platelet count available? ☒ Yes ☐ No [reset](#)

Platelet count?

Date Today D-M-Y

Is a separate nadir platelet count available? ☒ Yes ☐ No [reset](#)

Nadir platelet count?

Date Today D-M-Y

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](#)

Please select the relevant option for each question. If you select 'Yes', please provide the platelet counts using the free-text box available followed by the date.

Infant Platelet Counts Continued

Infant Platelet Counts

Data Access Group: Royal London Hospital

Editing existing Registry Identification Code (RIC) **test123**

Event Name: **First Registered Pregnancy (Arm 2: Pregnancy Registry)**

Registry Identification Code (RIC) **test123**

Please enter Infant Platelet Counts below.

Is a delivery cord or neonatal platelet count available? ☐ Yes ☐ No [reset](#)

Is a separate nadir platelet count available? ☐ Yes ☐ No [reset](#)

Is a delivery cord or neonatal platelet count available? (Infant 2) ☐ Yes ☐ No [reset](#)

Is a separate nadir platelet count available? (Infant 2) ☐ Yes ☐ No [reset](#)

Is a delivery cord or neonatal platelet count available? (Infant 3) ☐ Yes ☐ No [reset](#)

Is a separate nadir platelet count available? (Infant 3) ☐ Yes ☐ No [reset](#)

Is a delivery cord or neonatal platelet count available? (Infant 4) ☐ Yes ☐ No [reset](#)

Is a separate nadir platelet count available? (Infant 4) ☐ Yes ☐ No [reset](#)

Form Status

Complete? ☐ Incomplete

If the patient had multiple babies, please ensure the data for all are captured (questions relating to each infant will automatically appear on each form if you have specified that the patient gave birth to more than 1 baby in the 'Infant Details' form (please see slide 25 for more details).

Infant Thrombocytopenia Treatments

Infant Thrombocytopenia Treatments

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

Editing existing Registry Identification Code (RIC) ABC123

Event Name: First Registered Pregnancy (Arm 2: Pregnancy Registry)

Registry Identification Code (RIC) ABC123

Please enter Infant Thrombocytopenia Treatment below.

Did the infant have any treatment for thrombocytopenia? ☒ Yes ☐ No reset

Platelets ☒ Yes ☐ No reset

Date Today D-M-Y

Immunoglobulin ☒ Yes ☐ No reset

Date Today D-M-Y

Did the infant received a different treatment for thrombocytopenia? ☒ Yes ☐ No reset

Other, please specify

Date Today D-M-Y

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

If you select 'Yes' to the infant receiving platelets or immunoglobulins for treatment of their thrombocytopenia, you will be required to provide the date.

If the infant received a different type of treatment for their thrombocytopenia, please specify using the free-text box available.

Breast Feeding

Breast Feeding

Data Access Group: [No Assignment] ?

Editing existing Registry Identification Code (RIC) ABC123

Event Name: First Registered Pregnancy (Arm 2: Pregnancy Registry)

Registry Identification Code (RIC) ABC123

Please enter information about breast-feeding below.

Was the infant breast-fed during the first 3 months after birth? ☐ Yes ☒ No [reset](#)

If the infant was breast fed for less than 3 months, how many weeks was the infant breast fed for?

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 & Stay](#)

[-- Cancel --](#)

Please report whether the infant was breast-fed during the first 3 months after birth.

Using the free-text box available, enter the number of weeks the infant was breast-fed for if it was less than 3 months.

Completion of Data Entry

The UK ITP Registry

[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. If you wish, you may modify the events below by navigating to the [Define My Events](#) page.

☒ Choose action for record

NOTICE: Please note that Registry Identification Code (RIC) "ABC123" also exists on another arm.

Registry Identification Code (RIC) ABC123 successfully edited

Registry Identification Code (RIC) ABC123
Arm 2: Pregnancy Registry

Data Collection Instrument	First Registered Pregnancy <small>This is the first pregnancy enrolled on the Pregnancy Registry.</small>	2nd and Subsequent Pregnancies
Pregnancy Registration Details		
Clinician Information		
Obstetric History		
Problems In Previous Pregnancies		
Morbid Events In Previous Pregnancies		
Current Pregnancy Information		
Anthropometric and Lifestyle Information		
Bleeding Events During Pregnancy		
ITP Treatments During Pregnancy		
Supportive Therapies During Pregnancy		
Anaesthesia Method At Delivery		
Haematological Values During Pregnancy		
Coagulation Results At Delivery		
Details Of Delivery		
Maternal Outcome		
Comorbid Conditions During Pregnancy Or Up To 3 Months		
Infant Details		
Infant Morbidity		
Infant Platelet Counts		
Infant Thrombocytopenia Treatments		
Breast Feeding		

Click on a status icon to view event

Once you have completed the breast feeding form and selected "Save and Exit Form", you will have reached the end of entering data for this patient. You will then automatically be directed to the "Record Home Page" which should look like this. This patient record is now complete – as indicated by the green status icons beside each form.

Legend for status icons:

- Incomplete
- Incomplete (no data saved) ?
- Unverified
- Complete
- Many statuses (all same)
- Many statuses (mixed)

To alter any of the status icons, simply return to the relevant form and amend the form status (located at the bottom of the form) using the drop-down list 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

Thank you

Thank you for taking the time to enter your patients data onto our online database.

If you would like additional training on the general use of REDCap, please watch the video tutorial on how to enter data by copying and pasting the following link -

[https://redcap.vanderbilt.edu/consortium/videoplayer.php?video=data_entry_overview_01.flv&title=An Overview of Basic Data Entry in REDCap&referrer=redcap.qmul.ac.uk](https://redcap.vanderbilt.edu/consortium/videoplayer.php?video=data_entry_overview_01.flv&title=An%20Overview%20of%20Basic%20Data%20Entry%20in%20REDCap&referrer=redcap.qmul.ac.uk)

If you require further assistance with your data entry or have any general registry queries, please contact the team using the details below:

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The Royal London Hospital

Pathology and Pharmacy Building

80 Newark Street

London E1 2ES

Tel: +44 (0) 203 246 0473

Email: uk-itp.registryteam@nhs.net



Barts and The London
School of Medicine and Dentistry