The PURA Syndrome Global Patient Registry



Getting Started A User Guide

Before You Start

Account Authorisation

You will need to contact the Administrator of the PURA Syndrome Global Patient Registry to authorise your e-mail address for registration and access to the patient registry. To do this, contact <u>PURA@soton.ac.uk</u>

Once you have received an acknowledgement from the Administrator, you will be able to use your authorised e-mail address to register your login credentials and access the patient registry through the web portal. Please check your inbox and junk mail for an e-mail with the subject title 'PURA Patient Registry Account Activated'. You can use the embedded link to reach the patient registry.

Clinical Documentation & Laboratory Reports

It is strongly recommended that you have your child's laboratory report detailing their genetic diagnosis and any relevant clinical correspondence to hand when setting up your child's profile within the Patient Registry for the first time.

Duration

Allow 30 minutes to:

- create your login credentials
- setup your child's profile
- read and sign the electronic consent form

There are currently 9 modules within the Patient Registry. Depending on the level of detail provided, these could take quite a long time to complete. We would like to collect the most accurate information that we can, so please take your time. You do not need to complete all of the modules at once. Even a partly completed module can be saved for another day.

Important Information about the Patient Registry

The PURA Syndrome Global Patient Registry has been set up using an established secure healthcare database. There are limited options for development of the User Interface, which is aimed at healthcare professionals. Therefore, although as a parent or guardian you will be entering information about your child (who will appear as a 'participant' within the Patient Registry), there are some instances when you may be referred to as a 'clinician' or 'investigator' entering data on their behalf. Unfortunately, we cannot alter this terminology within the User Interface.

Support

Hopefully, this step-by-step guide will help to make the navigation of the site as easy as possible. Once you have set up your child's profile within the Patient Registry, completion of the various linked questionnaires should be straightforward.

However, if you do experience any problems with the Patient Registry, please contact: <u>PURA@soton.ac.uk</u>



- 1. Navigate to the homepage: <u>https://prod.tenalea.net/ciru/DM/</u>
 - a. If this is the first time that you are using the site, click 'I never logged in before' and create your account using the e-mail address that has been authorised by the PURA patient registry administrator
 - b. If you have already created an account password, enter your credentials to login

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Username Password	yourname@email.com					
I forgot my password ,	I never logged in before					
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2. Select the 'Participants' tab on the landing page



3. Click 'Add new participant'

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4. Add your child's initials in the 'participant initials' free text box, and then click 'Submit'

N.B. If you need to register more than one child, please ensure that the initials that you assign to each child enable you to easily distinguish between them

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5. Click 'Ok' in the pop-up box to acknowledge the registration of the participant. Then click 'Close registrationform'

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6. The participant details that you have entered should now be visible. Under the Dossier column, click 'Open'

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7. You will now see the participant forms screen. Click the 'Open' box, corresponding to Language choice



8. English is selected by default and there are currently no selectable options for other languages. Click 'Submit'.

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9. Click 'OK' in the pop-up box to acknowledge the form submission. Note that the Language choice option is now marked green



10. First click on 'Participant information', then click the 'Open' box, corresponding to Informed consent.

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11. Read the consent form and enter **your initials** in each free text box if you agree with the accompanying statement

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	1 I confirm that I have parental responsibility/legal guardianship and am the main custodian.	D-H
	2 I confirm that I have read and understand the information sheet (version 1.0) for the above study and have had the opportunity to ask questions.	D-H
	3 I understand that participation is voluntary and that I am free to withdraw my child at any time, without giving any reason and without medical care or legal rights being affected.	dh
	4 In the event that I withdraw my child from the study, I understand that data already submitted will remain in the study but that no further data will be requested.	
•	5 I understand access to relevant information contained within my child's medical records is required in order to conduct this research project.	
E E participant/Dossier - options	6 I understand that data will be held subject to the regulations on data protection (General	

12. Only when initials are provided in all 11 fields does the submit button appear at the bottom of the form. Click 'Submit'.

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	9 I am happy to be contacted by the research team during the study period.	D-H	
	10 I am happy to be contacted about future studies relevant to my child's condition. I understand there will be no obligation to take part.	D-H	i
	11 I agree to my child taking part in the above study.	D-H	l
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13. Click 'OK' in the pop-up box to acknowledge the submission of the consent form. Note that Informed consent is now marked green in the left-hand pane.

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14. Click the 'Open' box, corresponding to Demography Participant. Please note that completion of this form is <u>optional</u>.

N.B. Although this is optional, we would strongly encourage you to at least provide the following information: gender, DOB, county/state/country and genetic diagnosis.

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15. Next, expand the Participant Modules option

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M2P2 - Pregnancy, Birth and Newborn open	Gender	Male
M3P2 - Developmental Milestones Part 1 open		Female
M3P2 - Developmental Milestones Part 2 open		
MSP2 - Seizures and Epilepsy open	Date of Birth	
M6P2 - Growth open	Street name including number	
M7P2 - Endocrine open		
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16. Click the 'Open' box, corresponding to M1P2 - Genetics and Family History

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M5P2 - Seizures and Epilepsy	open	 Onder on On text on On text on 	Select.
M7P2 - Endocrine	open		
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17. The first module, Genetics and Family History, is now visible. This can be completed using a combination of radio buttons, drop down options and free-text fields.

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18. Scroll to the bottom of the page and click 'submit' to save the form (this can be done, even if the form is incomplete)

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19. Click 'OK' in the pop up box to acknowledge submission of the form. Note that the Genetics and Family History tab is now marked green.

N.B. The green tab does <u>not</u> mean that the form is locked. It can still be edited.



You can now go through the same process to complete the remaining modules



Editing Participant Modules

1. Select the 'Open' box for the form that you wish to edit (any forms for which data is already stored are marked green).



2. Edit the form as appropriate and then click 'Submit' at the bottom of the form.

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Exiting a form without saving any changes

1. If you wish to close the form without saving any data click 'Close Form' instead.



2. In the pop up that warns that closing the form may lose unsaved data, only click 'OK' if you are certain that you wish to exit without saving any data. Otherwise, click 'cancel' to return to the form.





Clinician Modules

• Note that the Clinician Modules cannot be created or edited by parents. However, once these have been completed by your child's clinician, they will be visible to you in read only form.





Returning to Participant list

1. Click the 'Close participantdossier' button to return to the participant list.



2. The following screen will be displayed:

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Logging out

• Click 'logout' to exit the patient registry

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