

## INPDR Quick Guide – V2.0

### A - Logging in

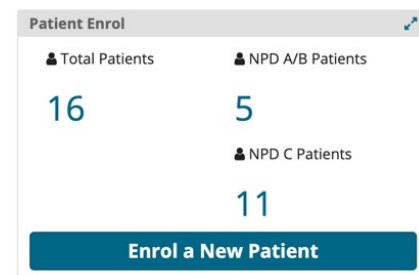
- 1) Visit <https://registry.inpdr.org>
- 2) Enter username and password
- 3) Click sign in

### B - Forgotten password?

- 1) Visit <https://registry.inpdr.org>
- 2) Click 'Forgotten Password? Click Here' and follow instructions

### C – Enrolling a new patient

- 1) Click 'Enrol a New Patient' on the landing page
- 2) Enter patient gender and date of birth and click next
- 3) Enter patient disease-specific details and click enrol
- 4) Record the Patient ID



### D – Entering Baseline data

- 1) Open patient record
- 2) Click 'Data Collection' on the side panel
- 3) In the Data Collection table, click 'Create' for Baseline event
- 4) Check the required data forms in the side panel to display the forms
- 5) After all data has been entered click 'Save'

#### Data Collection

Event	Status	Verified	Date	Scheduled	RAG	
C Baseline	Due			06/May/2019 - 05/May/2020		Create
Enrolment: INPDRC	Open		04/Jun/2019		<span style="color: green;">●</span>	Open

Enable Delete Buttons

**Add Medication**

**New C BASELINE**

- ✓ Assessment \*
- ✓ Laboratory Diagnosis \*
- ✓ NPC Family History \*
- ✓ NPC Clinical History \*
- ✓ Treatments
- ✓ Disability Scale \*
- ✓ Additional Investigations \*

**ASSESSMENT**

\* Assessment Date:

**BIOCHEMICAL AND GENETIC TESTING**

**Genetic Testing**

\* DNA testing performed:  Yes  No  Unknown

**Cytochemical Testing**

\* Filipin-test performed ?  Yes  No  Unknown

**Oxysterol Testing**

\* 7-Ketocholesterol tested:  Yes  No  Unknown

\* Cholestane-triol tested ?  Yes  No  Unknown

**E – Entering Encounter data**

- 1) Open patient record
- 2) Click 'Data Collection' on the side panel
- 3) In the Data Collection table click 'Add: X Encounter' (where X is the patient disease type)

Data Collection

Event	Status	Verified	Date	Scheduled	RAG	
C Baseline	Due			06/May/2019 - 05/May/2020		
Enrollment: INPDRC	Open		04/Jun/2019			

**F – Medical History and Comorbidities / Medication / Pregnancies / Adverse Drug Reactions forms**

The Registry allows for multiple records of the above forms to be completed.

- 1) Open patient record
- 2) Click on the required form on the side panel
- 3) Click on the Add button on the top right side of the screen (example of Add Medication button in Medication form)
- 4) Complete the form as required
- 5) The table will display all records completed for the patient (example of Medical History and Comorbidities table below)
- 6) Records can be opened by clicking on them within the table

**Medical History & Comorbidities** **Add Medical History & Comorbidities**

Description	ICD-10	Start Date	End Date	
Diarrhea	R19.7: Diarrhea, unspecified	03/Apr/2022		
Influenza	J10: Influenza due to other identified influenza virus	28/Mar/2022	01/Apr/2022	
Headache	R51: Headache	04/Jan/2022		
Seizure	G40.30: Generalised idiopathic epilepsy and epileptic syndromes, without mention of intractable epilepsy	06/Apr/2020		

Showing 1 to 4 of 4 entries

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## G – Patient Discontinuation/End of Data Collection

- 1) Open patient record
- 2) Click 'Data Collection' on the side panel
- 3) In the Data Collection table click 'Add: End Data Collection X' (where X is the patient disease type)

## H – Finding and Viewing Patient data

- 1) Click on the disease-specific Patient List
- 2) Click the Patient ID of the required patient
- 3) Click 'Data Collection'

## I – Managing Queries

- 1) On the centre landing page, click 'Manage Queries' in the Queries table
- 2) On the Queries page, view the table which lists all site queries
- 3) To quickly respond to the query, click on the query ID number in the query table and respond
- 4) To view the query within its form, click on the form name in the Event column
- 5) To respond to the query, enter the query answer in the 'Your response' box and click 'Answer Query'.

Queries							
Id	Created	Workflow	Owner	State	Patient	Field	Description
18	06/jun/2019	site from dm	Site	posted	NPAB-UKBI1-7	consent.consent_date	Please confirm Consent Date is correct

Manage Queries

### Your response

enter your response here

Leave as posted

Answer query



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