T1D REGISTRY: USER MANUAL

T1D: BACKGROUND AND STEP BY STEP INSTRUCTIONS

Type 1 diabetes (T1D) is a chronic autoimmune condition that affects the body's ability to produce insulin, leading to elevated glucose levels and severe health risks if untreated. Globally, an estimated 8.75 million people live with T1D, including 1.52 million children under 20.

Without proper care, children in low-resource settings often face misdiagnosis or inadequate access to essential healthcare, contributing to poor outcomes. To address this, a public-private partnership launched in 2009 provides free medicines and supplies to young people with T1D in low- and middle-income countries.

A key challenge for this initiative has been the lack of standardized, high-quality patient data collection. To improve patient outcomes and optimize treatment, Dure Technologies partnered with Novo Nordisk to develop a global T1D e-registry. This registry enhances data quality, supports research, and drives better care for children and young people with T1D.

This document provides step-by-step instructions for using the T1D registry:

1. Getting Started (Login And Create Account)
2. Understanding User Interface
3. New Patient Enrolment
4. Adding Registration Details
5. Patient History
6. Clinical And Pathological Examination
7. Treatment Plan
8. Tracking Outcome
9. Scheduling Appointments
10. Patient Dashboard
11. Summary
12. Patient Follow-up
13. Managing Records.

For convenience, a list of FAQs and best practices has been added at the end.

T1D USER MANUAL: STEP BY STEP INTRUCTIONS

STEP 1: GETTING STARTED

We have laid out some guidelines to support you through the process. To get started, you must paste the application link into your preferred web browser (Google Chrome, Microsoft Edge or Safari).

Once you have accessed the application page, click on the HCP button and enter your secure, authorized credentials into the appropriate fields *(Fig 1).* Post that, create a user pin for a two-step verification *(Fig 2).*

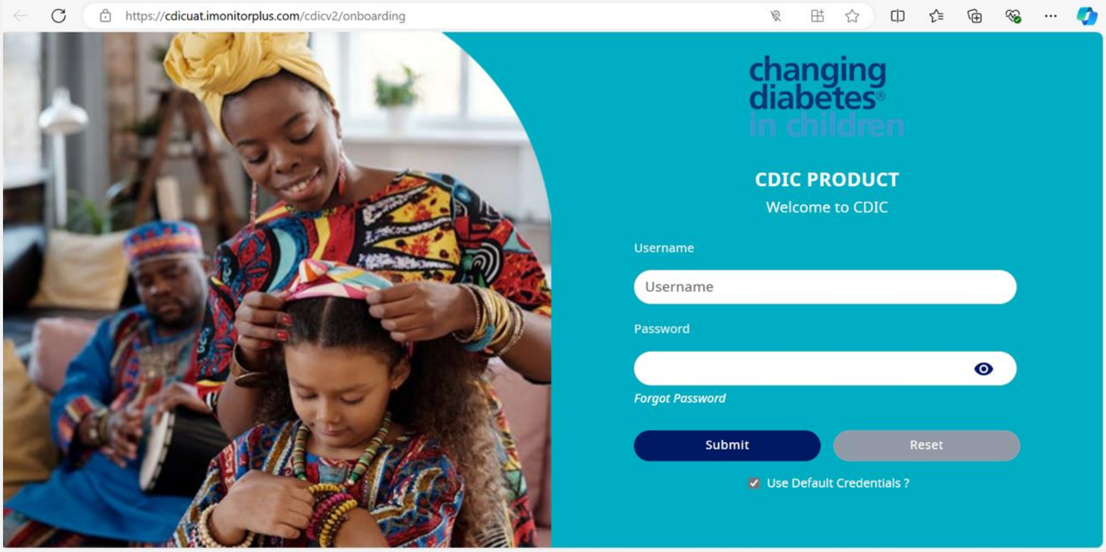


Fig 1.

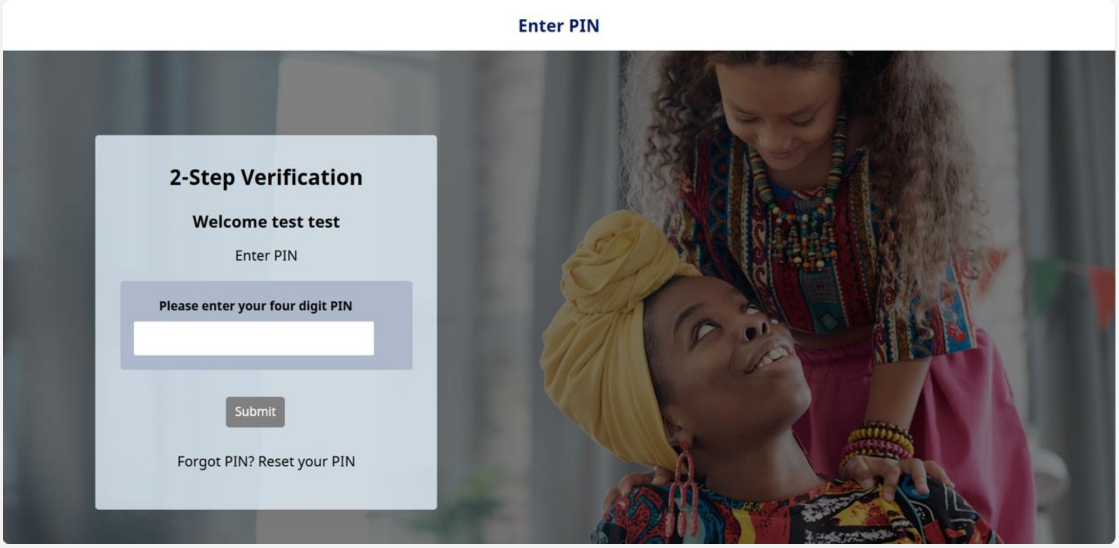


Fig 2.

Post authorization, you will be requested to submit your language preference to navigate the application *(Fig 3)*. Please note that you can switch between languages at any given point while navigating the application, further details are provided in succeeding sections.
The application will display a progress bar as it syncs data and sets it up for your use. Once the process is completed (usually takes a second or two) you will be redirected to your homepage which acts as a control centre for you to carry out your tasks in the unit. *(Fig 4)*

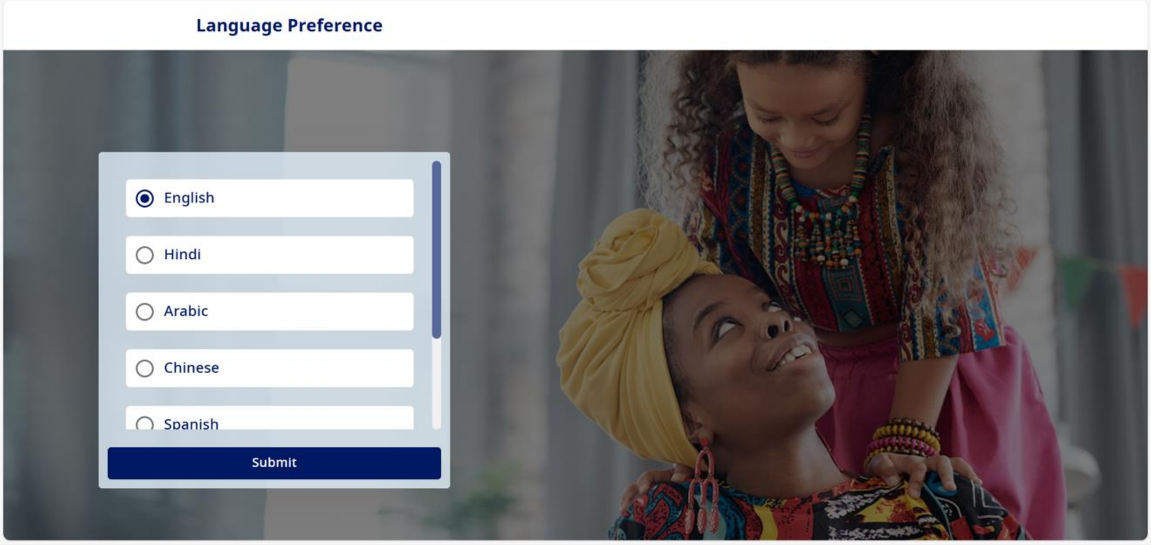


Fig 3.

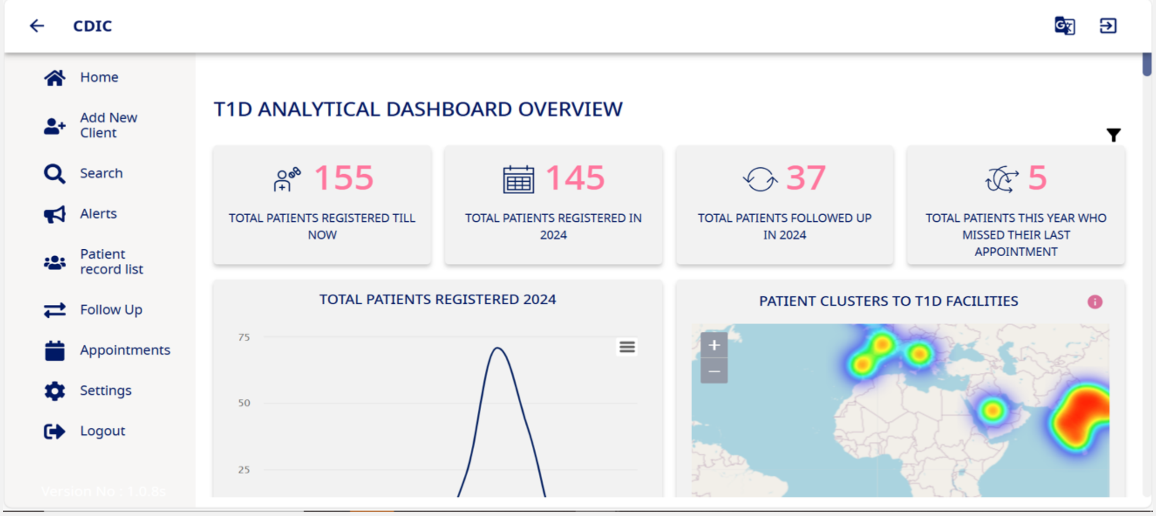


Fig 4.

STEP 2: UNDERTANDING USER INTERFACE

The homepage is designed to allow you to seamlessly navigate through the two form types and search for your patients with ease. Let's delve into the sections that you will be using most frequently and explore the capabilities of each. To start with, let's take a look at the options available on the header of the application.
The image above of the homepage has three icons marked out in blue which allow you to carry out the following actions -

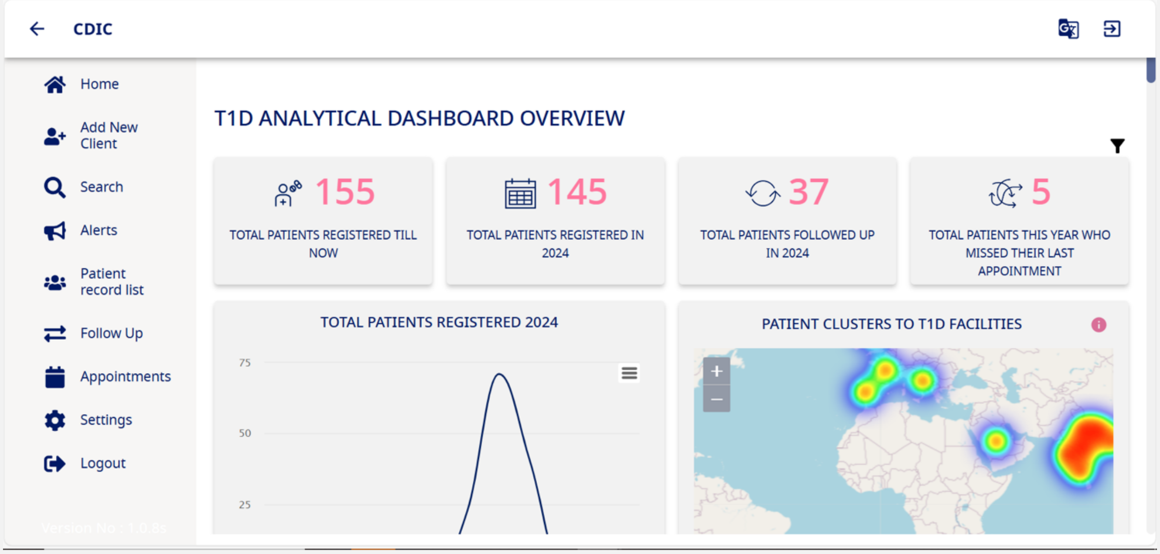


Fig 5.

1. Logout – When you have completed the data entry for the day and want to close your session, click on the logout icon at the top right corner of the header. You will be logged out.

2. Language change – Should you wish to change the language at any given point, select the preferred option from the dropdown list and the system will reflect the change.

Now let's take a look at some of the features that you will be using most often to capture the patient data and complete the entry in the CDIC e-Registry.

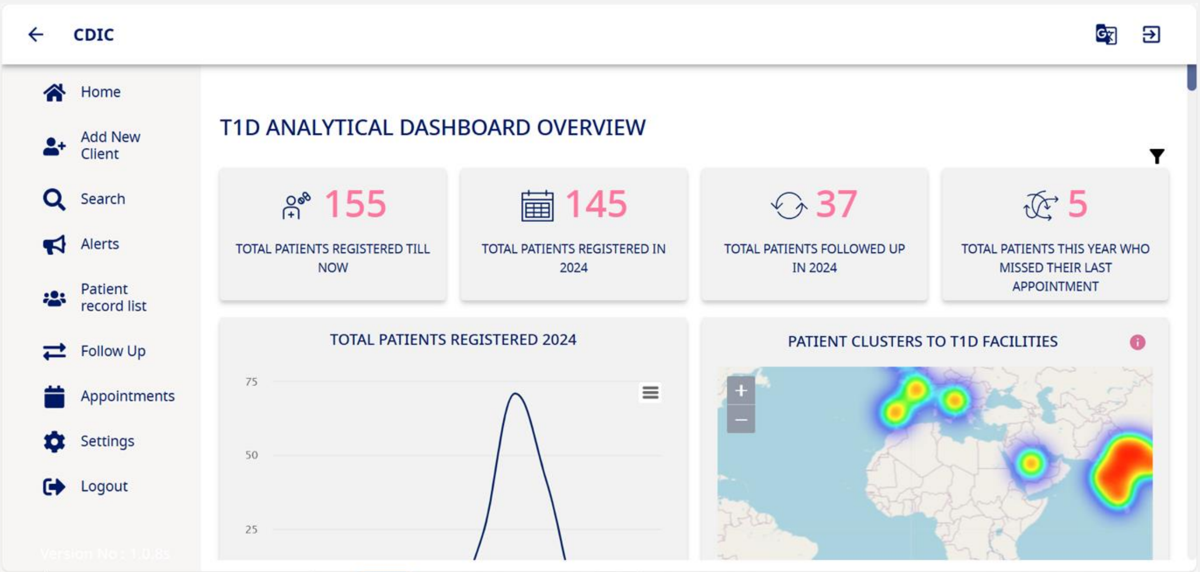


Fig 6.

Add New Client – Click on this button in the side menu to onboard a new patient into the system. This follows the Notification form requirements and will be covered in detail in the succeeding sections

Search – This functionality allows you to quickly search for an onboarded patient via their unique information like Name or UID

Follow Up – This feature is used to capture the details related to the Annual form and is used once a year (from the date of onboarding the patient in the system)

Patient Record List – This functionality allows you to view the list of patients you have onboarded and quickly jump to edit or add new information as required. Further details are in the succeeding sections. Please note that this feature is also available as an option in the sidebar menu too.

STEP 3: NEW PATIENT ENROLMENT

Notification Form

The notification form is designed to **onboard the patient** and capture primary details related to the due course of treatment and can be accessed via **"Add New Client"** option in the sidebar menu. In successive appointments, the updated details are captured in a "New Visit" allowing for continuity of the record. Let us delve into the various sections of this feature.

Steps to add New Client

1. Click on "Add New Client"
2. This will open up a search section of the application (see image below)
3. Confirm no duplicity of records by completing a search in the medical records database via
    a. Profile Page (parameters like Name, DOB)
    b. UID
    c. QR code.

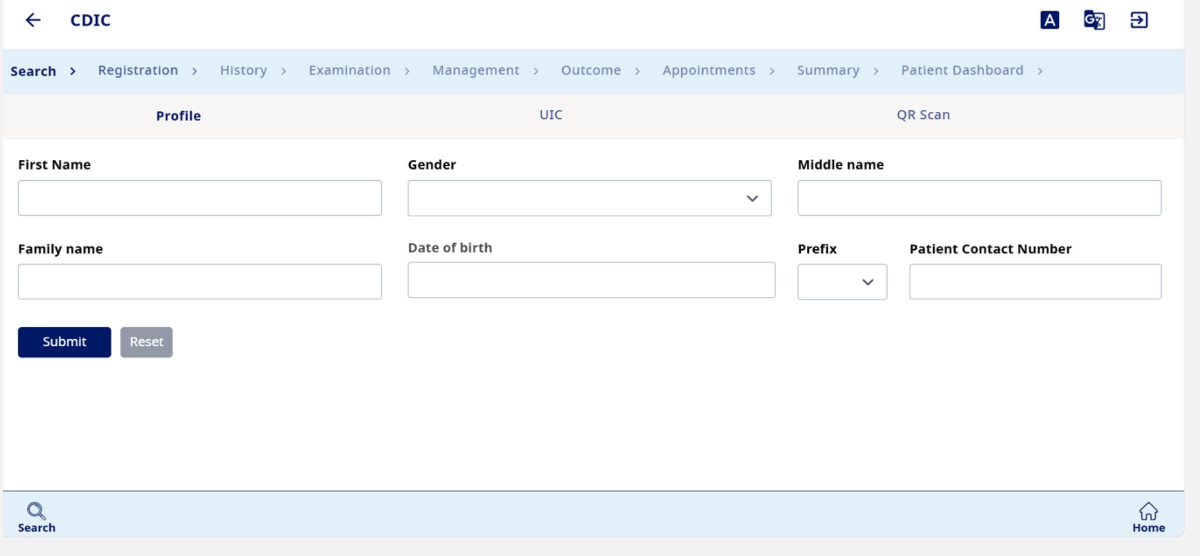


Fig 7.

STEP 4: ADDING REGISTRATION DETAILS

This section is designed to capture data related to the demographic & socioeconomic information related to the patient with T1D
Initiate the registration process by filling in details in the various sections (example: demographic details)

1. For fields like Date of Registration and Date of Birth, the calendar will pop-up and you can switch between years by clicking on the year at the top left corner of the pop-up box
2. To choose between the months, use the ‘<’ and ‘>’ buttons on either side of the pop-up box
3. Click on the desired date in the calendar when you have finished steps 2 & 3
4. The selected date will be displayed in the field (Fig 1: Date Fields)
5. For fields like Sex or Ethnicity that have a dropdown, click on the field and the menu list will be displayed
6. Click on the desired option and it will reflect in the field (Fig 2: Dropdown Fields)
7. Follow the process for all fields in the sections to complete the registration
    a. Demographic Details
    b. Socioeconomic Details
    c. Mortality of the Parent
8. Once done, click on the ‘Submit’ button below to complete the registration stage

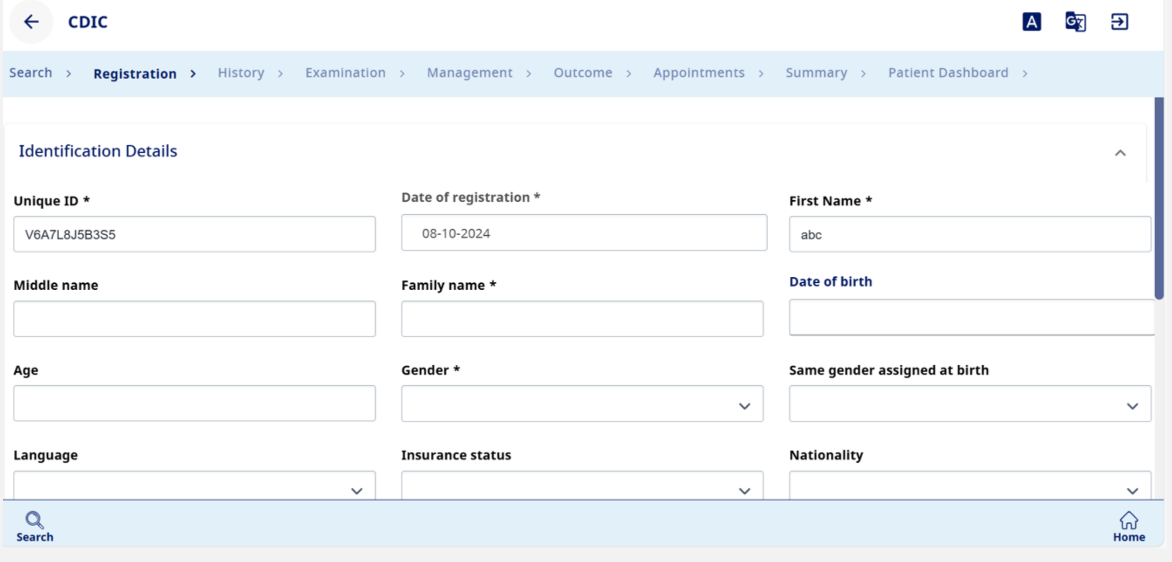


Fig 8.

STEP 5. PATIENT HISTORY

This section is designed to capture data related to the clinical information related to the patient with T1D like clinical presentation, comorbidities etc.
For capturing multiple data points in a response, the checkbox option allows you to tick as many answers as applicable. Post completion of the clinical data entry, click on the Submit button to proceed to the next stage of the registry, namely Examination.

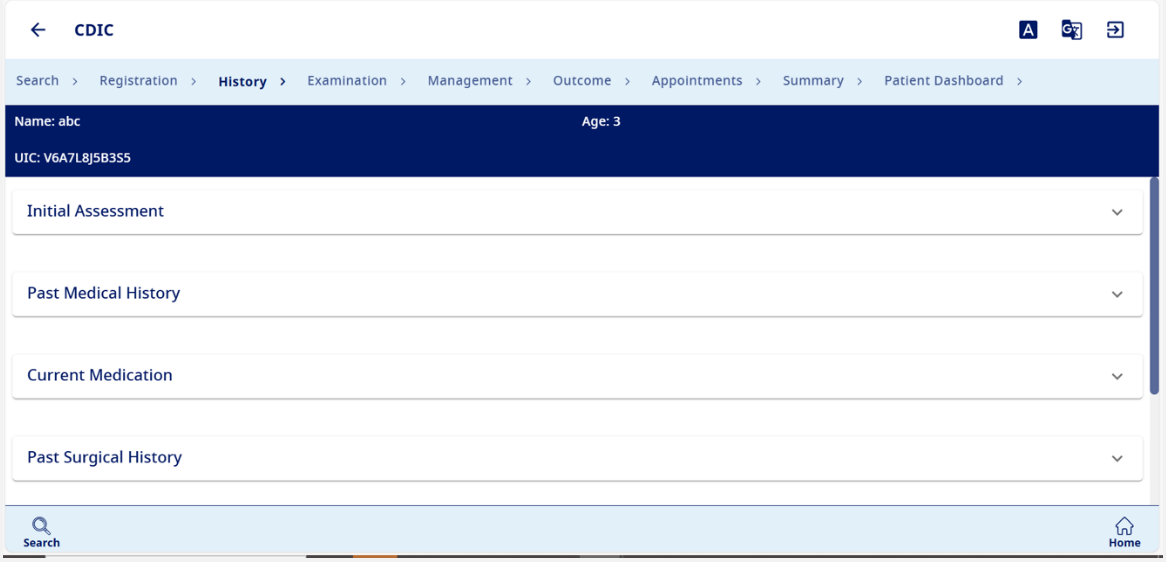


Fig 9.

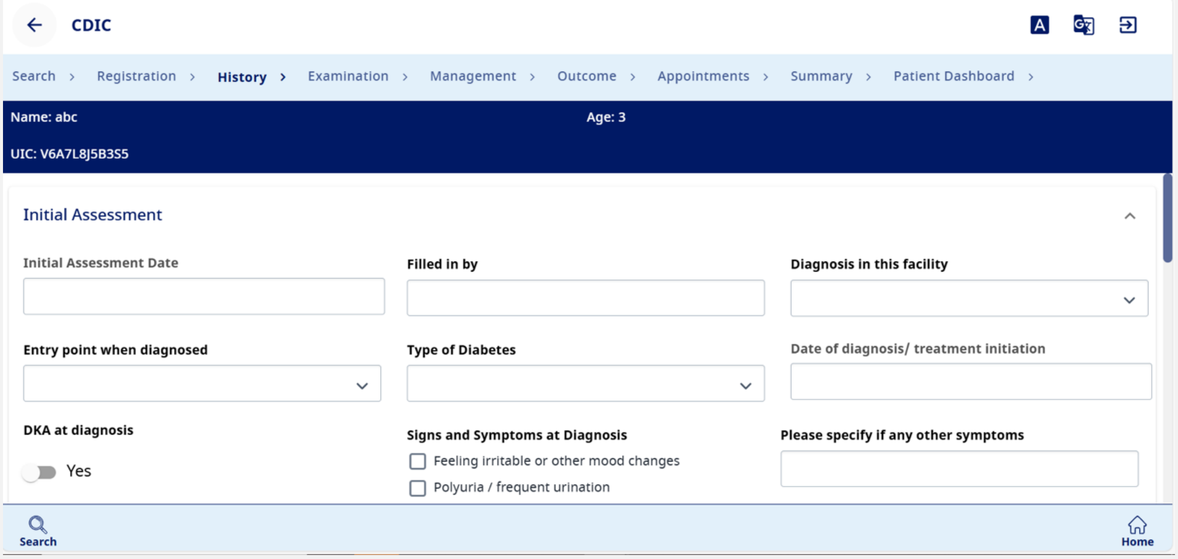


Fig 10.

STEP 6: CLINCAL AND PATHOLOGICAL EXAMINATION

This section is designed to capture data related to the assessment, clincal measures, complications and lab investigation information related to the patient with T1D.

1. The lab values stage has free text fields to capture data related to blood glucose levels, HbA1C etc.
2. Post date entry in the lab values section, proceed to enter the data in the antibodies section
3. Post completion of the data entry for this stage, click on submit and proceed to the next stage, namely Management.

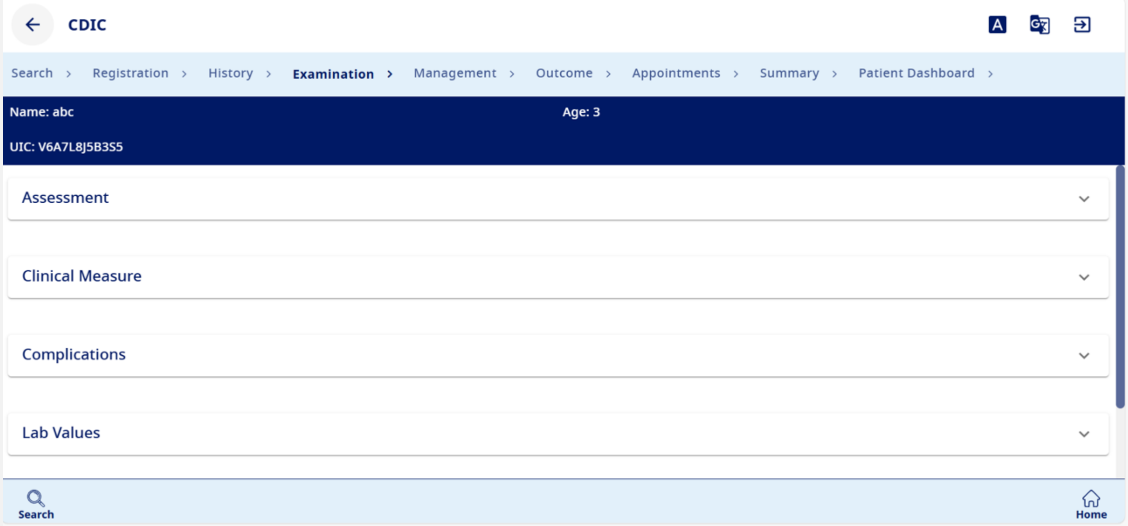


Fig 11.

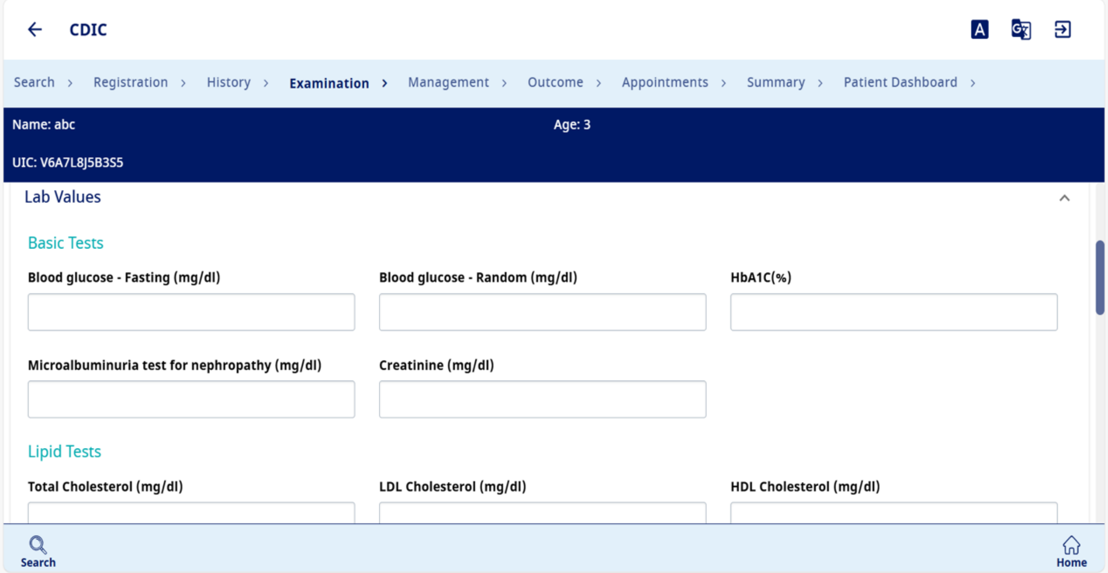


Fig 12.

STEP 7: TREATMENT PLAN

This section is designed to capture data related to the insulin & concomitant medication information related to the patient with T1D

1. Complete the information in the insulin regimen section
2. Complete the information in the non-insulin (glucose lowering) medication section
3. Complete the information in the other medical therapies section
4. Click on submit once you are done and proceed to the next stage

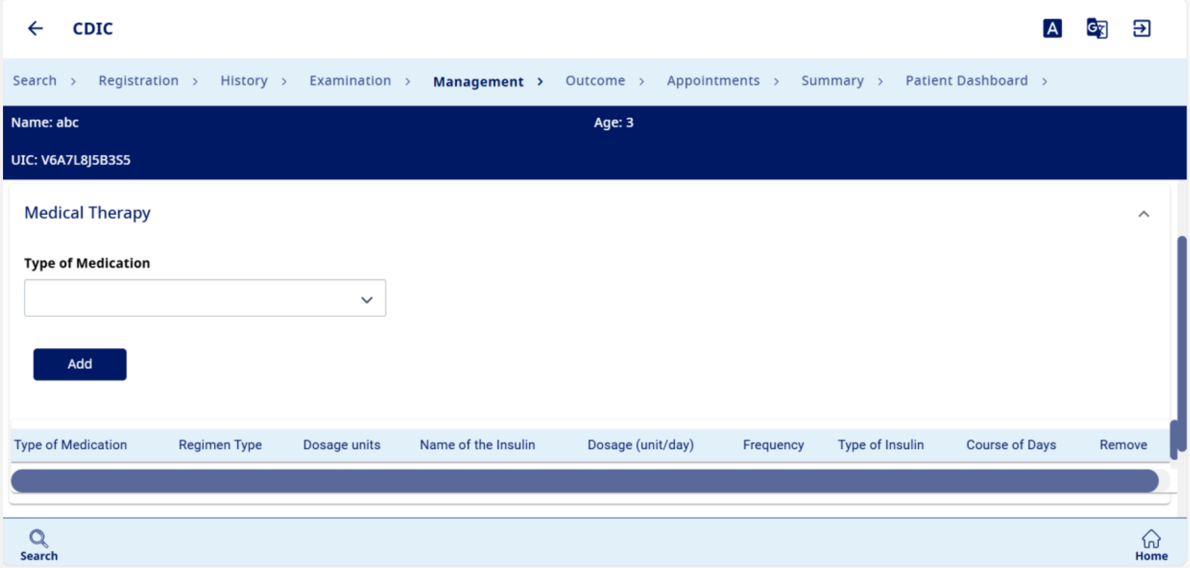


Fig 13.

STEP 8: TRACKING OUTCOME

Additionally, you can keep a record of outcome for each patient by clicking on change status and selecting Yes or No from the drop-down menu.
Further, you can select the reason for change in status under the patient status drop-down menu.

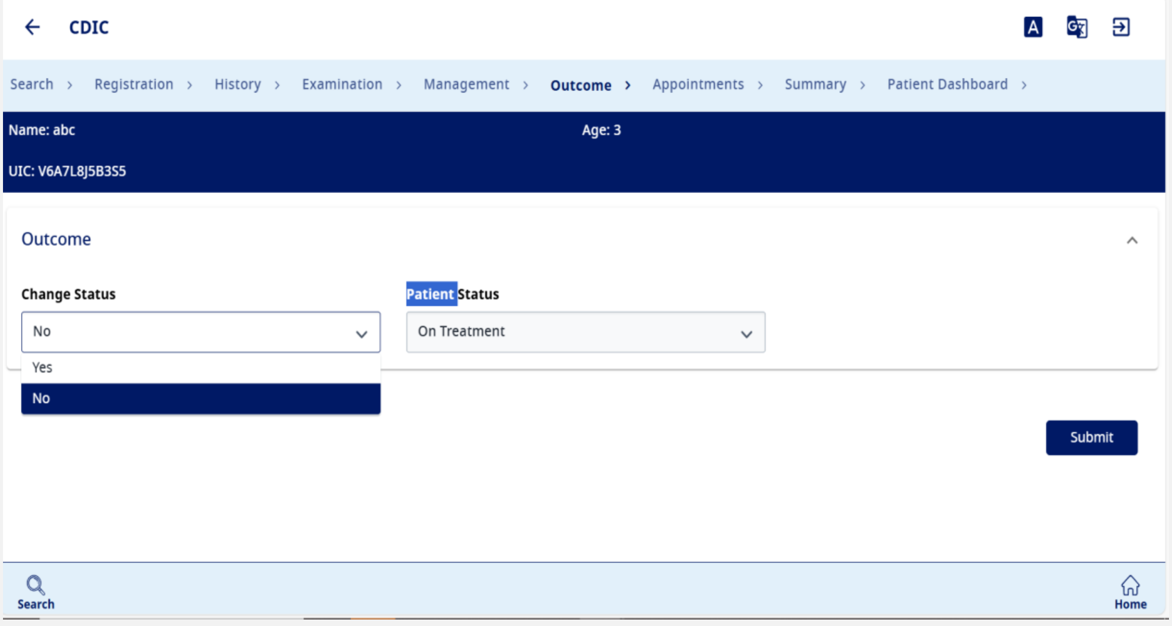


Fig 14.

STEP 9: SCHEDULING APPOINTMENTS

1. Interactive Calendar: The dashboard includes a calendar view showing all scheduled appointments. You can add appoinetment details for each patient and track as well as review appointment history, helping to ensure consistent patient engagement.
2. Alerts and Notifications: The system generates alerts for upcoming appointments, lab tests, and medication refills. Alerts are prioritized based on urgency, helping providers focus on the most critical tasks first.

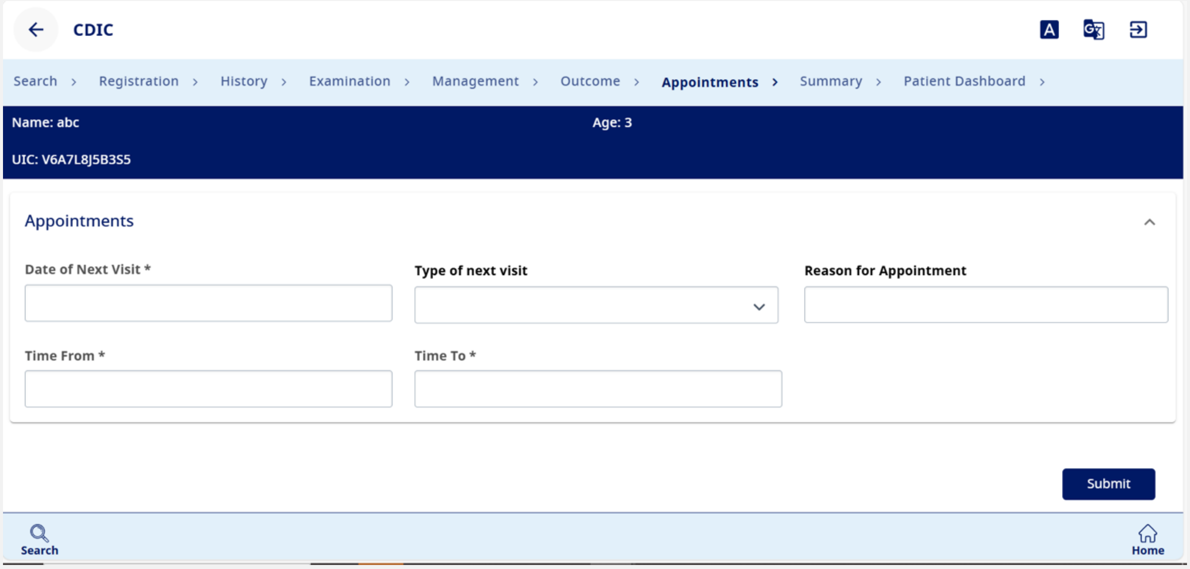


Fig 15.

STEP 10: PATIENT DASHBOARD

The patient dashboard allows data to be visualized through various chart types such as line graphs, bar charts, making it easier to detect patterns and make informed decisions. Following are the details that can be viewed on the dashboard.

1. Demographic Details
2. Socioeconomic Details
3. Location
4. Vitals/Medical History
5. Treatment Regimen
6. Lab Values
7. Alerts regrading treatment monitoring and Health Assessment

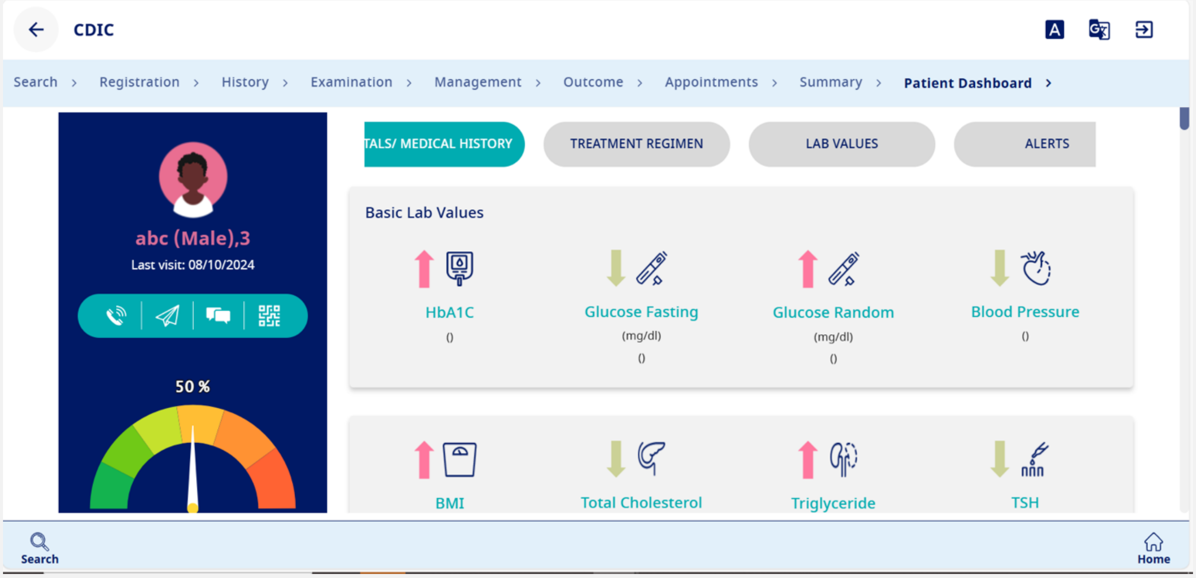


Fig. 16

STEP 11: SUMMARY

This section is designed to review the information of the newly onboarded patient and there is a provision to export a pdf of their case summary

1. Click on the close button of the popup to acknowledge completion of case recording
2. Review data entered for accuracy and completeness
3. Click on download summary to export the pdf
4. Click on the home icon at the bottom right corner of the screen to exit the Notification Form.

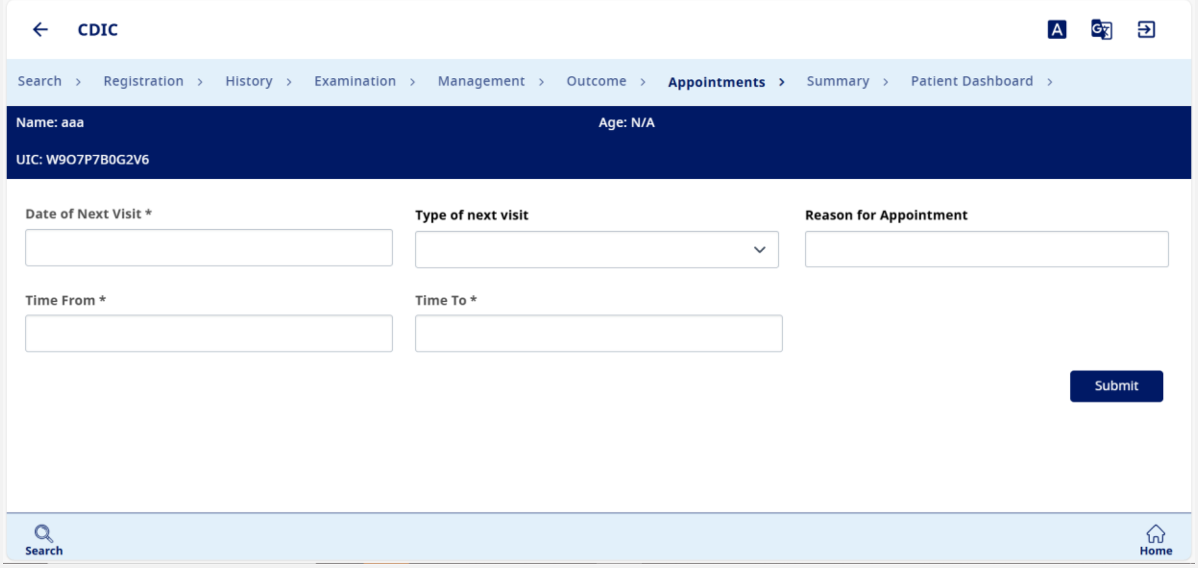


Fig. 17.

STEP 12: PATIENT FOLLOW-UP

The annual form is designed to **review and update the patient records** related to the due course of T1D treatment and can be accessed via **"Follow Up"** option in the sidebar menu. The frequency of data entry is once a year, from the date of onboarding the patient into the system.

1. Click on the follow up icon on the side menu of the Homepage
2. You will be redirected to a new page with a search bar
3. Enter the patient name in the search bar to retrieve the medical records from the database
4. In case there are multiple patients with the same name, scroll through the summarised patient details by clicking on the dropdown arrow on the right side and select the appropriate one.
5. Click on the 'Follow Up' text at the bottom of the summarised patient details
6. There are 13 sections in Annual form, please update the information for each section.
7. Post completion of data entry, click on the Submit button at the bottom right corner of the screen
8. You will be redirected to the summary page with a pop-up confirming successful record capture
9. Acknowledge successful case completion by clicking on the 'Close' button of the pop-up message
10. To export as a PDF, click on the 'Download Summary' button.
11. Click on the Home icon at the bottom right corner of the screen to exit the form and be redirected to the homepage.

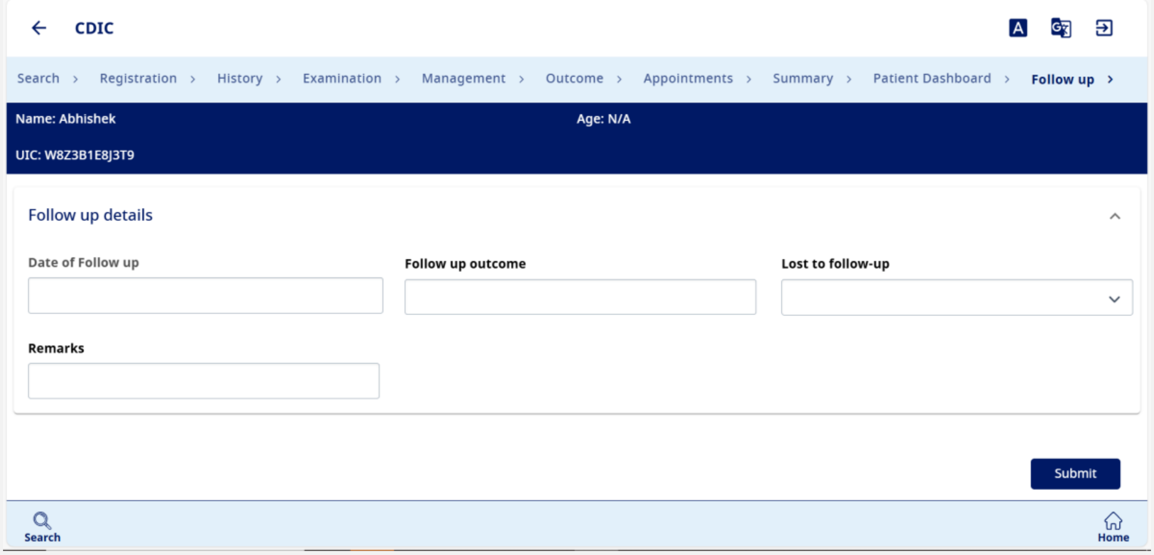
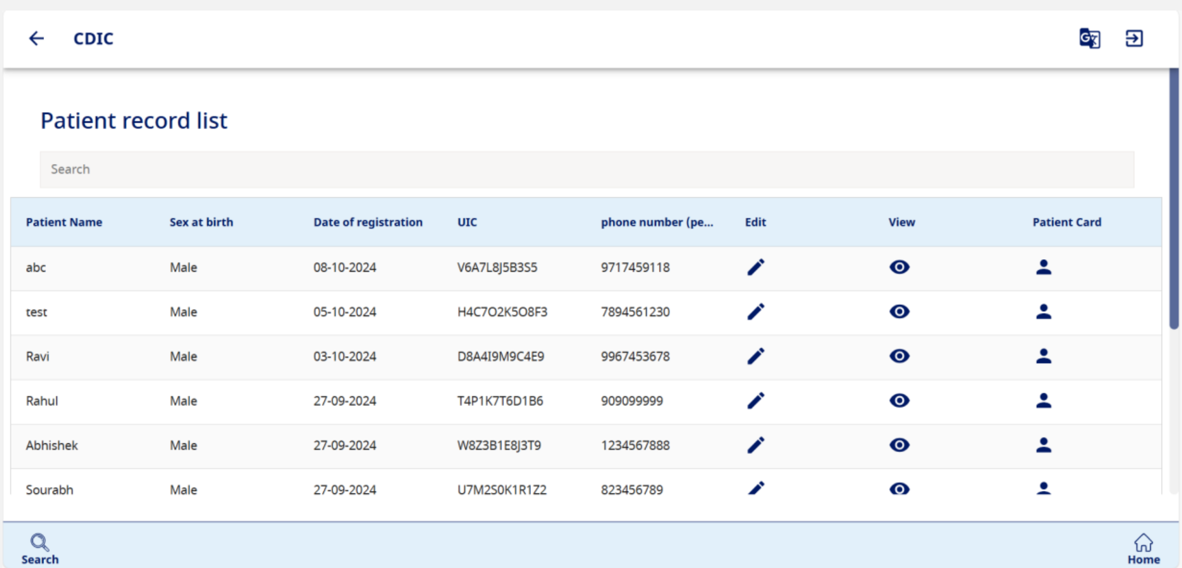


Fig. 18.

STEP 13: MANAGING RECORDS

In the due course of treatment, it is anticipated that the patient will be visiting the facility once in three months to review and update their treatment plan. New information related to their treatment can be recorded in the Notification form section under “New Visit” by following the steps outlined below:

Click on the patient record list button on the homepage or select the option from the side menu
Use the search bar to pull the pertinent patient record from the database.
Click on the edit option (pencil icon) to enter new information related to that patient
For changes related to the Registration section, update the new information in the field and it will be reflected in the database (example : insurance status, number of people in household)
For recording the new information related to the clinical data, scroll to the bottom of the page and click on ‘New Visit’
This will cause the fields to be reset to blank values so you can enter new information.
When done, click on Submit.
Follow steps 5-7 for each stage till you reach the summary stage.
Post a review, you can export the case report as a pdf by clicking on the ‘Download Summary’ button
Click on the home icon at the bottom of the screen to be redirected to the Homepage



Patient Name	Sex at birth	Date of registration	UIC	phone number (pe...	Edit	View	Patient Card
abc	Male	08-10-2024	V6A7L8J5B3S5	9717459118			
test	Male	05-10-2024	H4C7O2K5O8F3	7894561230			
Ravi	Male	03-10-2024	D8A4I9M9C4E9	9967453678			
Rahul	Male	27-09-2024	T4P1K7T6D1B6	909099999			
Abhishek	Male	27-09-2024	W8Z3B1E8J3T9	1234567888			
Sourabh	Male	27-09-2024	U7M2S0K1R1Z2	823456789			

Fig. 19..

FREQUENTLY ASKED QUESTIONS (FAQS)

Here's some information you may find useful if you're facing any trouble navigating the platform:

- **I need to add new information for a patient onboarded 6 months ago. How do I proceed?** To add new information, follow the steps in the "Managing Records" section of this document. Please note that it is only possible to add new information for a patient who has been onboarded onto the system. If not onboarded, they will have to be registered as a new patient

- **I need to fill the Annual form. Where is it?** The Annual form can be found under "Follow Up" which is a menu option on the Homepage. For further details on navigation and data entry, refer to the section "Annual Form"

- **I need to fill the Notification form for a new patient. What should I do?** The Notification form can be accessed under "Add New Client" which is a menu option on the Homepage. For further details on navigation and data entry, refer to the section "Add New Client". To update information for a patient already in the system, refer to the "Managing Records" section.

BEST PRACTICES AND TIPS

Here are some tips you might find useful while entering patient data in the registry

- For recording the patient name, always ensure you capitalize the first letter and try to follow the name as on the government issued ID card for data integrity

- For quantitative/ numerical data like height and weight, be mindful of the unit you are entering the data in to maintain continuity in the registry across centers

- Never share your username and password as it exposes your patient's data to risk. Log out of your account once you have completed data entry for the session.