# REGISTRY.I-DSD.ORG | User Manual

## CONTRIBUTOR/CENTRE LEAD MANUAL

# Glossary

| Term | Meaning |
|------|---------|
| Software<br>Website<br>Tool<br>Registry<br>System<br>Web App<br>Web Application | These terms all identify the registry.i-dsd.org web based software. |
| QOS | Quality of service |
| Audit trail | The audit trail is a log of all the CRUD actions on the registry. |
| CRUD | Create Read (View) Update Delete - indicates all actions on an entity. |
| Entity | The entities are data structures.<br>Examples of entities in the tool: *Record, DSD assessments, CAH assessments*, etc<br>The entities are identified by an ID that is unique to the system. |
| ID Identifier | A number identifying an entity. |
| Record | This word refers to an instance of the registry (i.e. a patient) |

# Abstract

The purpose of this document is to illustrate how the registry.i-dsd.org website is organized. The registry is a web based software that allows users grouped in centres to have a specific role. Depending on the role, each user interacts differently with the tool: the menu items and the page within the tool have different levels of permission.

# Requirements

## User requirements

To use the tool, the user needs **a valid user account** that can be requested from the home page through the "Request an account" button (see the image below).
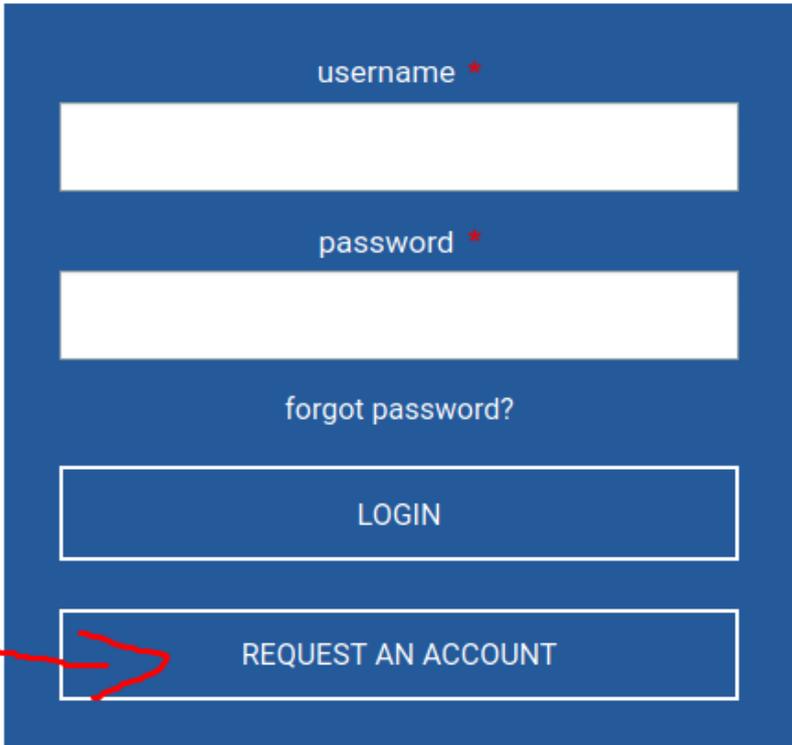


For further information on the registries, please visit
I-DSD registry and I-CAH registry.

In the page linked by the "Request an account" button you will find a form to fill in with the required data.

> **CREATE NEW ACCOUNT**

*To request a user account for the Registry, please complete the following form.*

*If you cannot remember username or e-mail address, please send an email to registry@i-dsd.org.*

**Email address** *

A valid email address. All emails from the system will be sent to this address. The email address is not made public and will only be used if you wish to receive a new password or wish to receive certain news or notifications by email.

**Password** *

Password strength:

**Confirm password** *

Passwords match:

**Full Name** *

**Phone Number**

**If you have forgotten your password** there is a link stating "forgot password?" that allows you to restore it; the system will email you at the address you have supplied during the "forgot password" procedure.

**If you do not remember your email address** you can send an email to registry@i-dsd.org.

# System requirements

## Hardware and software

The tool is a web application so to use it all you need is a web browser.

The supported browsers are the following:

- Microsoft Edge | version 40+
- Firefox | version 30+
- Safari iPad | version 4+
- Chrome | any version

Note that in the website there are uploadable/downloadable files, Types allowed: txt, csv, xls, xlsx, pdf.

## Supported screen resolutions

The tool is designed to work with devices with common tablet screens and larger ones.

The screen resolution should be a minimum of 1366 * 768 pixels

# The Home Page

Everything starts from the home page of the registry which is reachable at the web address registry.i-dsd.org. From this page it is possible to Log in to the registry (with a valid user account) or visit other free access pages through the links and the buttons that are present in this page.

In addition to the following links, for users:
- forgot password - you need the email address related to your user account;
- request an account - for a new user only.

There are also information links:
- I-DSD website link;
- I-CAH website link;

and
- Terms and conditions;
- Information and consent forms;

# Common elements usage

## Structure of the page

The webpage, once successfully logged in, is composed as follows, from top to bottom.

- HEADER
  The part of the page that is on top with, from left to right:
    - Logo - if you click on it you will reach the login page.
    - Main menu - with main links you need.
    - User menu - with the link to the profile and the "logout" link.
- BODY
  That is where the link you have clicked or the action you have performed is loaded.
- FOOTER
  that is the bottom of the web page, containing, from left to right:
    - Secondary menu - with information links
    - Credits - with University of Glasgow logo
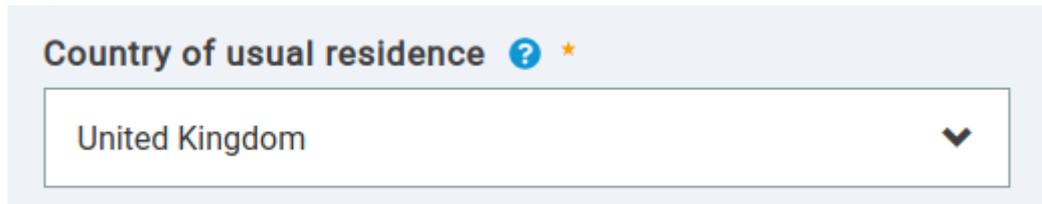
# Forms

The website is composed of input types, such as:
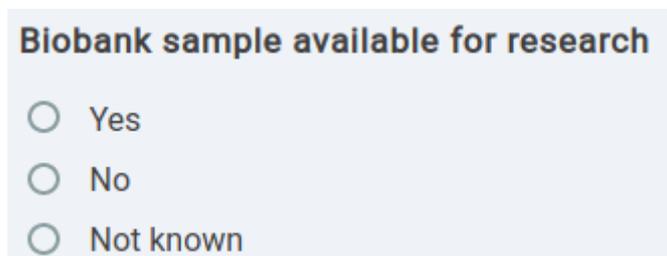- textfield

**Local ID** ❓

**Country of usual residence** ❓ *

United Kingdom ⌄

- radio buttons

**Biobank sample available for research**

○ Yes
○ No
○ Not known
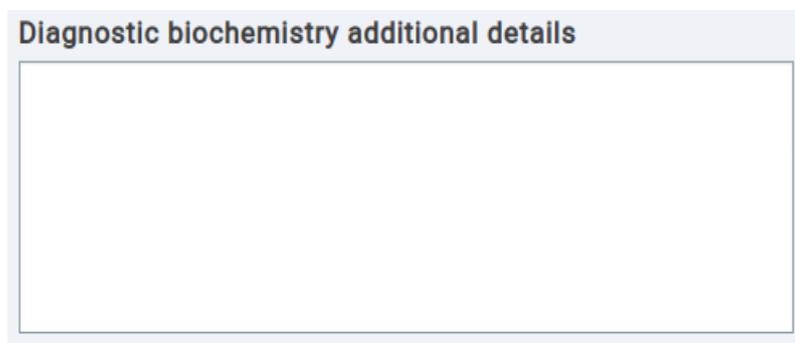
- text areas

**Diagnostic biochemistry additional details**
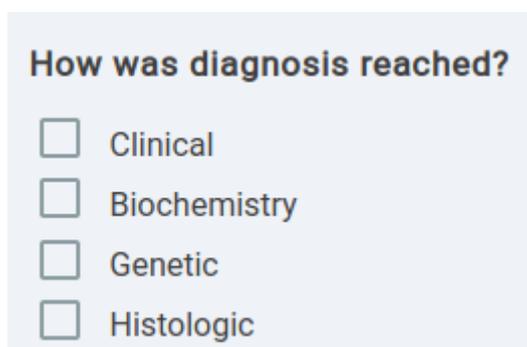
- checkboxes

**How was diagnosis reached?**

☐ Clinical
☐ Biochemistry
☐ Genetic
☐ Histologic

Each form input is composed by a Label, the bold title of the input.
When a field is marked with a red asterisk it is considered a **required field**, you cannot submit a form without filling the required fields.

## Inline help

The inline help, represented by a question mark in a blue circle is designed to provide a contextual help to the user.
On touch screen devices it is enabled on "tap" action, on standard desktops devices it is enabled on mouse hover.
The image that follows represents the inline help attached to the label of the "Country of usual residence" field.



## Sections

Sections are collectors of fields, which collapse and expand when clicked.
In the following example 'Consent' is expanded, whereas 'Core Information' is collapsed.



Meaning of the label "CONSENT (1/4)"
This section is expanded (open).
The text "CONSENT" is the name (or title) of the section, the numeral 1 indicates the number of fields that are already completed, the numeral 4 is the total number of fields in the section.

Below "CONSENT (1/4)"  - "required 1/1" means that in this section there is 1 required field and it is already completed.

Meaning of label "CORE INFORMATION (5/6)".
The section in collapsed (closed), but the extent of completeness of the form is indicated: 5 fields out of a total of 6 are already completed.

If there are no required fields, "required 0" will be displayed.

# Tables

Tables are useful for presenting sets of data.
This table displays a list of "CENTRE RECORDS" in summary form.

**CENTRE RECORDS**

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | | | Q FILTERS | ADD RECORD |

| REGISTRY ID | YEAR OF BIRTH | CURRENT GENDER | KARYOTYPE | DISORDER TYPE | ACTUAL DIAGNOSIS | COUNTRY AND CENTRE | ACTIONS |
|---|---|---|---|---|---|---|---|
| 4602 | 2013 | Male | 46 XY | Congenital Adrenal Hyperplasia | 21-hydroxylase def (CYP21A) | United Kingdom - Glasgow RHC | ○○○ |
| 4599 🔍 | 1999 | Male | 46 XY | Congenital Adrenal Hyperplasia | 21-hydroxylase def (CYP21A) | United Kingdom - Glasgow RHC | ○○○ |

This table is provided as an example to illustrate how it is possible to interact with a table in the registry.
The header of the table is where the titles are placed, column by column.
The rows represent an entity or an aggregation of data.

The column title is clickable, **you can sort the column** by clicking on the column name.

The last column is usually dedicated to the "**Actions**" you can perform on that specific row.
In this case the icon is represented by three dots, by clicking on it you can access other actions depending on your level of permission.

**Filtering a table** is possible using the orange "Filters" button. Clicking on the "Filters" shows which data can be filtered. The filters can be reset to go back to the standard view.

The tables show a limited number of results in a single page. At the bottom of a table, a **pagination** widget can change the results page.
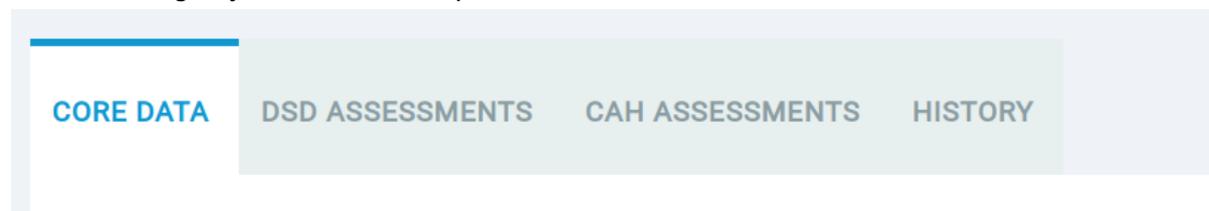Eg.

| 4319 | 2017 | Male | 46 XY | Non-specific disorder of undermasculinisation | Isolated hypospadias | United Kingdom - Glasgow RHC | ○○○ |
|---|---|---|---|---|---|---|---|

| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | ›› | Last » |
|---|---|---|---|---|---|---|---|---|---|---|

## Record structure

Record or registry instance is composed of:



- CORE DATA
- DSD Assessments (1 registry instance (patient record) can have many DSD Assessments)
- CAH (Only for records having Disorder Type "Disorder of androgen excess" or "Congenital Adrenal Hyperplasia")
  - First presentation (a single instance)
  - CAH Assessments or CAH Longitudinal data (1 registry instance (patient record) can have many CAH Assessments)

Click on the tabs to move between interfaces
The only tab that does not represent an entity is the "History" one, where the user can find the whole history of a record (all editing, with dates, authors etc.)

# Security and Operations

- Pages containing forms are protected from an unintended exit of the user with an alert message, to let the user confirm that they are quitting the page;
- The system is programmed to perform an automatic logout after 30 minutes of inactivity;
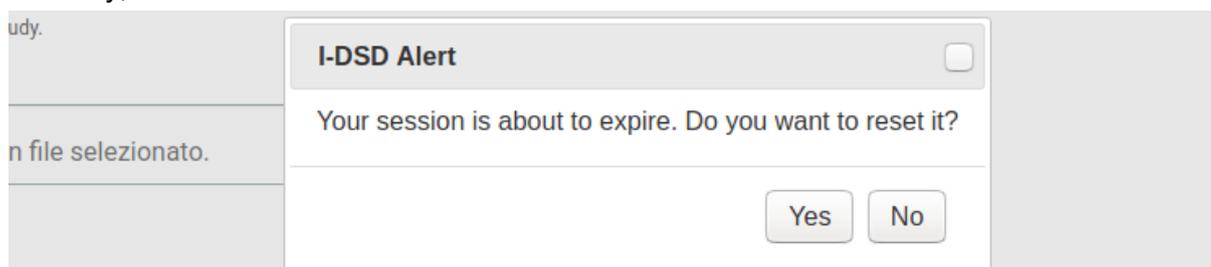


- Each user action is tracked in an audit trail;
- Contextual help is provided during the usage of the tool. The icon (a question mark within a blue circle) is discrete enough to be ignored by frequent users and prominent enough to be noticed by novices;
- The website front end design is made to be simple, intuitive and linear.

# The Roles Of The Contributor?

Each Contributor can perform the following functions after having successfully logged in:

- View all the records
- Create a record
- Edit a record
- Request patient access
- View record audit trail
- Edit his/her profile (email, password and personal data)
- View his audit trail

## View all records

All records of a centre are shared with all clinical contributors in that centre.

Records are accessible from different areas of the web site.

## Dashboard

In the Dashboard page (the home page for all users of that centre), a Contributor is able to view 2 tables:

- Centre records
- Records created by the User (My Record List)

Centre records and My Record List are summary tables, with filters and pagination.
On the top of each list there is the "Add record" button.

These two links are also accessible from the main menu clicking on the menu items:
- "Centre records";
- "My record list".

The record list is presented in a table, where the first column is "registry id", which is a positive integer number.
If the record contains a Research file (one or more attachments of a scientific research result), it is displayed beside the record id number.
See the following screenshot.

| REGISTRY ID | YEAR OF BIRTH | CURRENT GENDER | KARYOTYPE | DISORDER TYPE | ACTUAL DIAGNOSIS | COUNTRY AND CENTRE | ACTIONS |
|---|---|---|---|---|---|---|---|
| 4602 | 2013 | Male | 46 XY | Congenital Adrenal Hyperplasia | 21-hydroxylase def (CYP21A) | United Kingdom - Glasgow RHC | ooo |
| 4599 🔖 | 1999 | Male | 46 XY | Congenital Adrenal Hyperplasia | 21-hydroxylase def (CYP21A) | United Kingdom - Glasgow RHC | ooo |

In this image you can see an icon beside the Registry ID.

# Create record

This function is performed through the "Add record" button on record summary tables (such as the ones on the dashboard or clicking the menu item labelled "Add new record".



Irrespective of how the "Add record" page is reached, a new record can be added into the system by filling the required fields of the form.

In some pages, such as the one provided as an example, you have "<< Back" link to come back to the previous page.

# Edit record

Edit a record is exactly the same as adding it, with the difference that the record already exists. So first of all, you need to reach the record page that you want to edit.
To do that you can filter the list of records by "ID" or whatever filter you choose from "filters" (on top of record list).

An example of filtering by ID



This list has been filtered by "Registry ID" (4599)

Once the record is displayed you can click on the Action icon (the 3 dots) and then the "Edit" link.
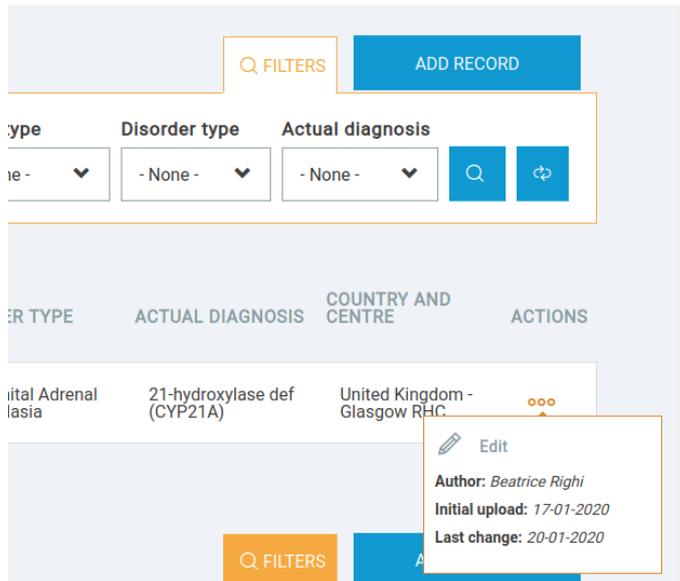


The edit record page is exactly the same of the add record one.

> EDIT RECORD

**PATIENT INFORMATION SUMMARY**

| REGISTER ID | LOCAL ID | YEAR OF BIRTH | SEX AT BIRTH | CURRENT GENDER | DISORDER TYPE | ACTUAL DIAGNOSIS | KARYOTYPE |
|---|---|---|---|---|---|---|---|
| 1255 | CAH0004 | 1990 | Female | Female | Disorder of androgen excess | 21-hydroxylase def (CYP21A) | 46 XX |

The request patient access has been successfully forwarded. You will be notified at any change. Record successfully saved. ×

**CORE DATA**    DSD ASSESSMENTS    CAH ASSESSMENTS    HISTORY

# Request patient access

From the add/edit record page, it is possible to request patient access.
The "Require patient access" checkbox has to be flagged and the field "Patient's email" has to be completed.

Once you have saved the record a notification is sent to the registry auditor who will approve the request.

The message stating "The request patient access has been successfully forwarded. You will be notified at any change. Record successfully saved.", confirms that the invitation process has been started.



# View record audit trail

The record audit trail is visible by clicking the "History" tab;.

The History page will show a filterable table with the CRUD history of the current record.



# Edit your profile
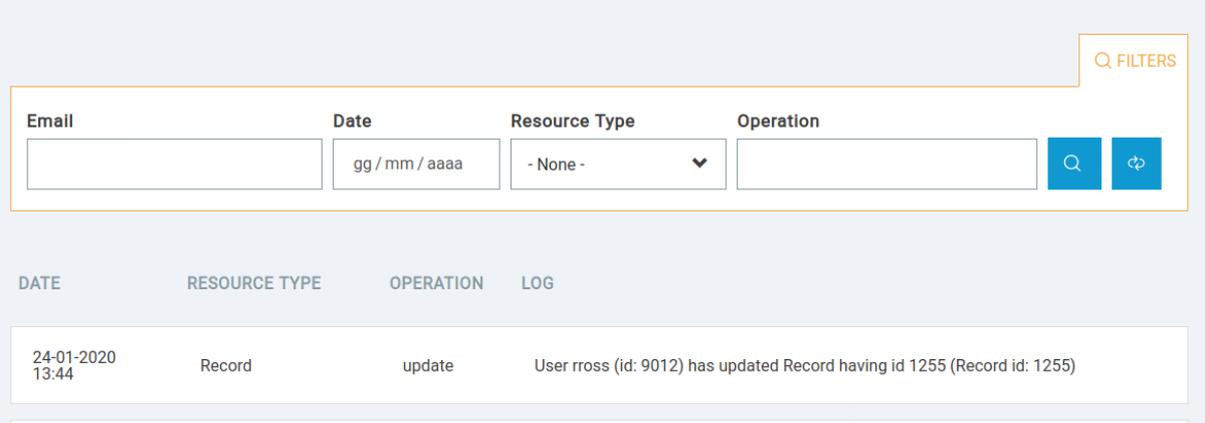


A logged in user can edit all user data including:

- Password
- Email address
- Full Name
- Phone Number
- Position
- Address
- Professional Society

The fields "Centre Name" and "Country" are not editable.

# View your audit trail

To access your audit trail you can click on "Audit trail" on the main menu.

**> AUDIT TRAIL**

| | | FILTERS |
|---|---|---|

| Email | Date | Resource Type | Operation | | |
|---|---|---|---|---|---|
| | gg / mm / aaaa | - None - | | 🔍 | ↺ |

| DATE | RESOURCE TYPE | OPERATION | LOG |
|---|---|---|---|
| 24-01-2020 13:44 | Record | update | User rross (id: 9012) has updated Record having id 1255 (Record id: 1255) |

The audit trail will show a table with: Date, Resource Type, Operation and Log (the human readable message) as columns.
It is possible to filter the list using the filters.

# The Additional Roles Of The Centre Lead

In addition to the roles of the Contributor, each Centre Lead can also:

- Delete a record
- View his/her Centre audit trail
- Manage Users (block/unblock Contributor' accounts in their centre)

## Delete record

Only the Centre Lead is allowed to delete a record. To delete a record you must access the record page as you would do in edit.
A delete button is available and a confirm message will pop-up when it is selected.

required * 4/4

**⌄ FAMILY HISTORY (2/5)** ──────────
   required 0

**RESEARCH RESULT**

e.g. Can be a dataset from a study.

**Add a new file**

[ Sfoglia... ] Nessun file selezionato.

❓ Upload requirements

*The fields with an asterisk are mandatory.

[ SAVE ]   [ DELETE ]

The delete button is hidden for all users except the centre lead.

## View your Centre audit trail

To access your audit trail or your centre audit trail if you are a "Centre Lead", click on the "Audit trail" link on the main menu.

## Manage Users

Centre lead can block/unblock all users belonging to his centre.
To access manage users' functionality, as Centre Lead, click the main menu item "Manage users".

A Centre Lead is able to block/unblock by clicking on the Action link on the right.