REGISTRY.I-DSD.ORG | User Manual

PATIENT MANUAL

Glossary

Term	Meaning
Software Website Tool Registry System Web App 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. Examples of entities in the tool: *Record, DSD assessments, CAH assessments* etc. The entities are identified by an ID that is unique in the system.
ID Identifier	A number identifying an entity.
Record	This word is referring 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 **a valid user account** is needed. To get an user account, the Patient User must be invited by a Contributor or a Centre Lead.

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 don't 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 you are 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 home 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 informative links
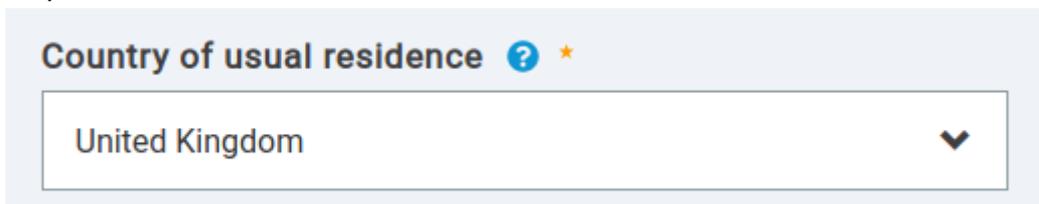 - ○ Credits - with University of Glasgow logo

Forms

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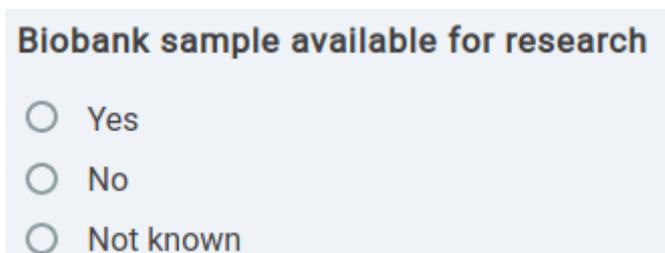- ● textfield

Local ID ❓

- ● dropdown list

Country of usual residence ❓ *
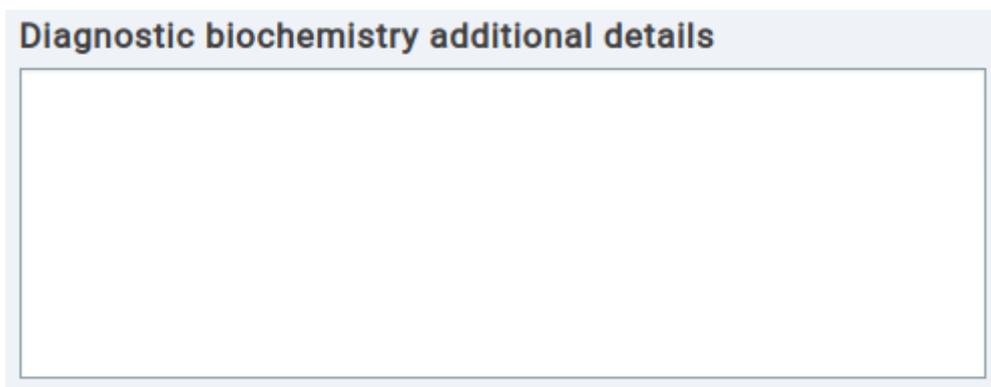
United Kingdom ⌄

- ● radio buttons

Biobank sample available for research

- ○ Yes
- ○ No
- ○ Not known

- ● text areas

Diagnostic biochemistry additional details

- checkboxes

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 made of 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.
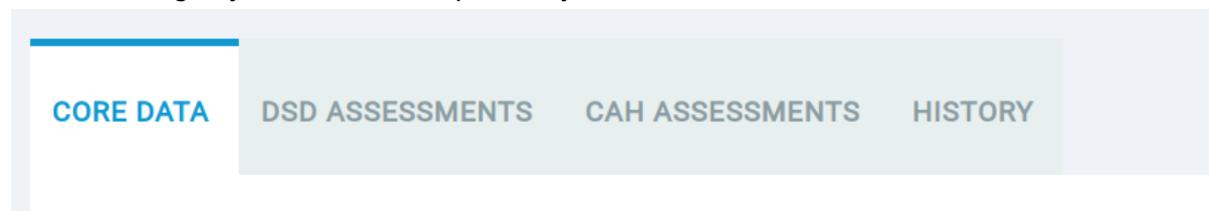Eg.

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 by:

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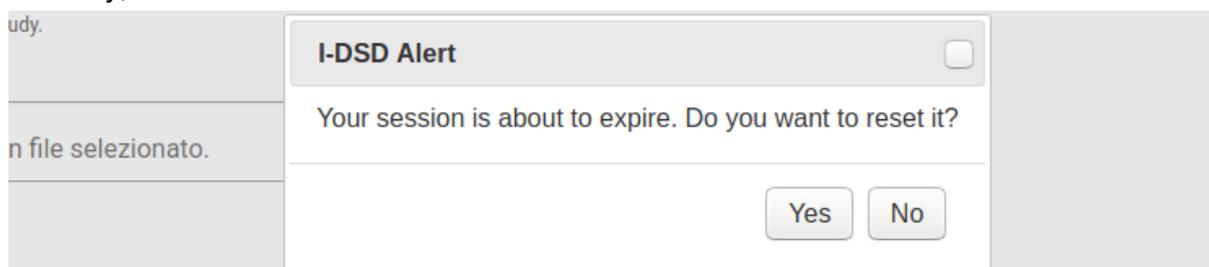
- Each user action is tracked in an audit trail;
- Contextual help is provided during the usage of the tool. It's icon (a question mark within a blue circle) is discrete enough to be ignored by frequent users and prominent enough to be noticed by novices;
- The website front end design is made to be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

Patient account request

A patient can request an account to view their data through the clinician (a Contributor or Centre Lead) who will add the patient's email address to start the process. Once the request of a user account has been forwarded, it has to be approved by the auditor

After the validation the "invited" patient will receive an email confirming that a user account has been successfully created.

What can a Patient do?

Patients can currently do the following:

- Choose a password (on first login)
- View their data
- Request a deletion of their data

Choose a password (on first login)

This an example of the email received by a patient.

Dear Patient

Via your doctor, you have requested access to your data in the I-DSD/CAH
Registry. To access the registry, please click on the following link and
follow the instructions to create a user account in I-DSD/CAH Registry.

Create User Account
http://idsd.mvls.gla.ac.uk/user/reset/3489/1587030820/tI-WuhBr2tmTVjOhUNtG-4xinoRbe9i6FQkZg3mV-O8

If the link does not work, please copy the following link and paste it into
your browser.

LINK:
http://idsd.mvls.gla.ac.uk/user/reset/3489/1587030820/tI-WuhBr2tmTVjOhUNtG-4xinoRbe9i6FQkZg3mV-O8

If you have any questions or need help to set up your account please contact
registry@i-dsd.org

Yours sincerely

Centre Doctor Name

Centre Name

As you can see the patient is invited to complete the registration process.
Clicking the link will lead the patient to a page in which a password needs to be created to gain access.
Once the password has been set, the user (patient) is logged in and is able to see the dashboard with all their data.

View data

From this page is possible to navigate in "read only" mode through the data that has been previously filled in by a Clinician.

Dashboard

My Profile
Patient

Logout

> 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

CORE DATA   DSD ASSESSMENTS   CAH ASSESSMENTS

<< Back

Responsible clinician: Professor Peter Parker   **Reg. ID:** 1255

▲ CONSENT (1/1)
required * 1/1

☑ Consent for registry *

I confirm that I have obtained the consent of this patient to use his or her information as described in the Informed Consent and have retained a suitable record of that consent.

Data can be shared for research purposes

○ Yes
○ No
◉ Not known

Can be contacted for research purposes

○ No
○ Yes

Request a deletion of their data

At the end of the "CORE DATA" page is a button stating "Request record deletion":.

∨ CORE INFORMATION (0/0)
   required 0

∨ BIRTH (0/0)
   required 0

∨ DETAILS OF CONDITION (0/0)
   required 0

∨ FAMILY HISTORY (0/0)
   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.

REQUEST RECORD DELETION

If the patient clicks the button, a confirmation page will be loaded.

Dashboard

My Profile
Patient

Logout

> PATIENT DELETION REQUEST

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

CORE DATA   DSD ASSESSMENTS   CAH ASSESSMENTS

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You are requesting the deletion of this patient account, this action can not be undone! Are you sure you want continue?

CONFIRM   Cancel

Only after the "confirm" button is clicked will the deletion request be forwarded to the auditor for action.