

REGISTRY.I-DSD.ORG | User Manual

CONTRIBUTOR/CENTRE LEAD MANUAL

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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: <i>Record, DSD assessments, CAH assessments, etc</i> 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)

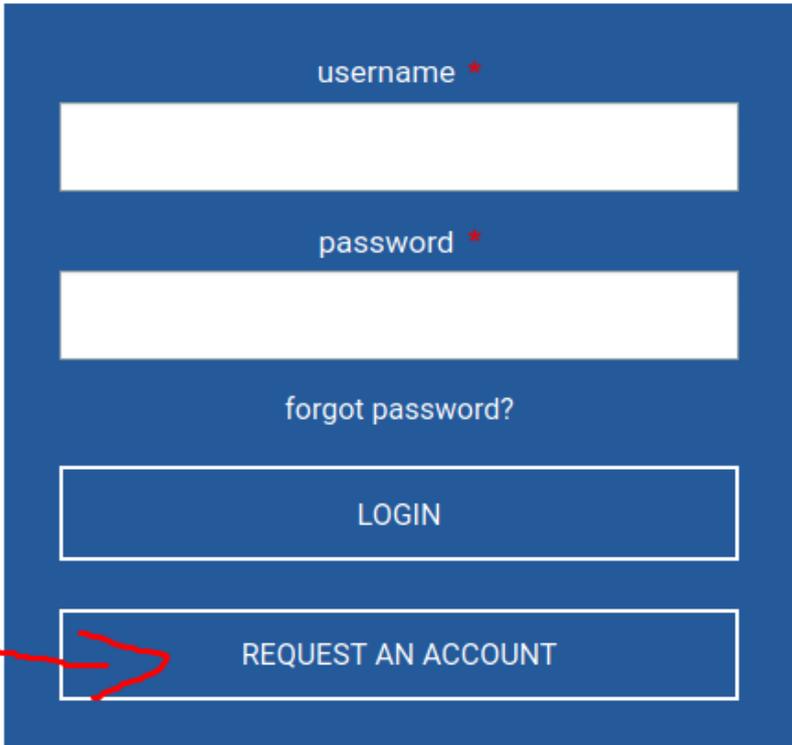
Abstract

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).



The image shows two logos at the top: the I-DSD registry logo on the left and the I-CAH registry logo on the right. Below the logos is a blue rectangular form with white text and input fields. The form contains the following elements from top to bottom: a label 'username' with a red asterisk, a white input field; a label 'password' with a red asterisk, a white input field; the text 'forgot password?'; a blue button with white text 'LOGIN'; and a blue button with white text 'REQUEST AN ACCOUNT'. A red hand-drawn arrow points from the left side of the form to the 'REQUEST AN ACCOUNT' button.

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 * <input type="text"/> <small>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.</small>	Password * <input type="password"/> <small>Password strength:</small>	Confirm password * <input type="password"/> <small>Passwords match:</small>
Full Name * <input type="text"/>	Phone Number <input type="text"/>	

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

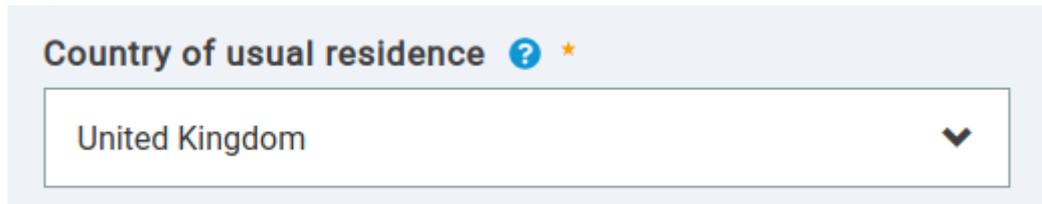
The website is composed of input types, such as:

- textfield



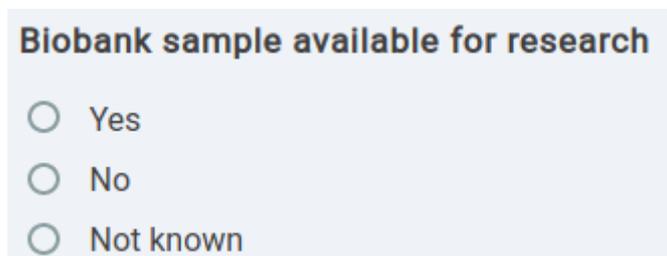
A screenshot of a textfield input. The label is "Local ID" in bold black text, followed by a blue circular help icon containing a white question mark. Below the label is a rectangular text input box.

- dropdown list



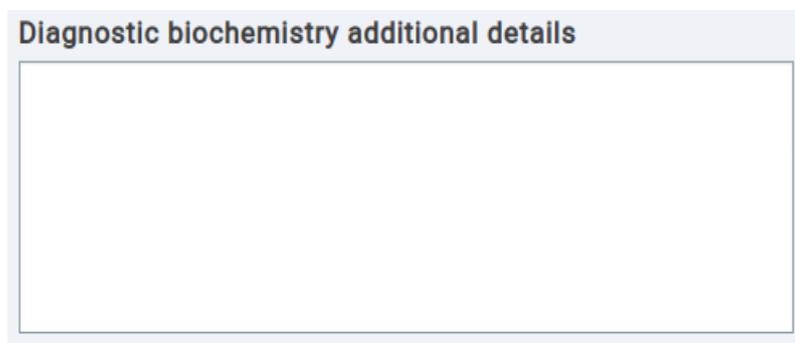
A screenshot of a dropdown list input. The label is "Country of usual residence" in bold black text, followed by a blue circular help icon containing a white question mark and a red asterisk. Below the label is a dropdown menu showing "United Kingdom" and a downward-pointing arrow.

- radio buttons



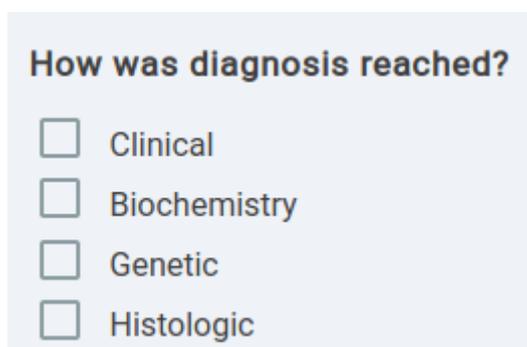
A screenshot of radio buttons. The label is "Biobank sample available for research" in bold black text. Below the label are three radio button options: "Yes", "No", and "Not known".

- text areas



A screenshot of a text area input. The label is "Diagnostic biochemistry additional details" in bold black text. Below the label is a large rectangular text input box.

- checkboxes



A screenshot of checkboxes. The label is "How was diagnosis reached?" in bold black text. Below the label are four checkbox options: "Clinical", "Biochemistry", "Genetic", and "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.

The image shows a form field labeled "Country of usual residence" with a question mark icon and an asterisk. The field contains the text "United" and a dropdown arrow. A tooltip box is displayed over the field, containing the text: "Please select the country where this record was added". Below the field, the label "First contact with centre" is visible.

Sections

Sections are collectors of fields, which collapse and expand when clicked.

In the following example ‘Consent’ is expanded, whereas ‘Core Information’ is collapsed.

The image shows a form with two sections. The first section is titled "CONSENT (1/4)" and is expanded. It contains a checkbox for "Consent for registry" which is checked, and a text area for "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." There are also radio buttons for "Data can be shared for research purposes" with options "Yes", "No", and "Not known", and a checkbox for "Require patient access". The second section is titled "CORE INFORMATION (5/6)" and is collapsed. It has a "required 0" label.

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 is 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

🔍 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.

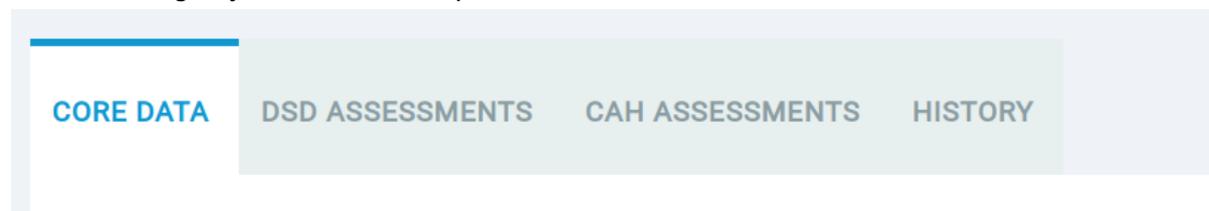
Eg.

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:



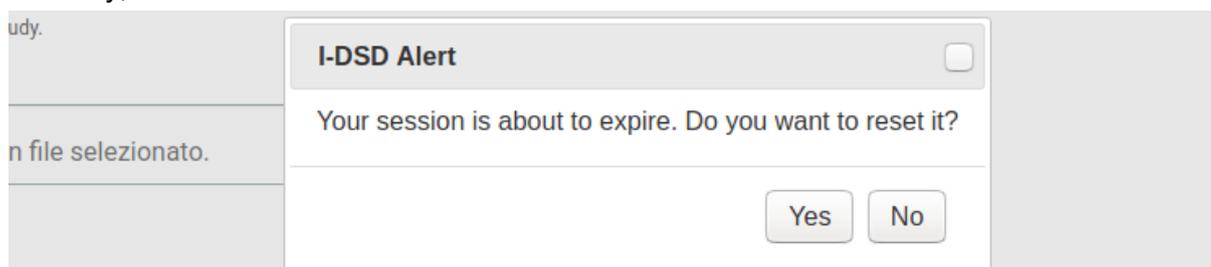
- CORE DATA
- DSD Assessments (1 registry instance (patient record) can have many DSD Assessments)
- CAH (Only for records having Disorder Type “Disorder of androgen excess” or “Congenital Adrenal Hyperplasia”)
 - First presentation (a single instance)
 - CAH Assessments or CAH Longitudinal data (1 registry 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	...
4599 	1999	Male	46 XY	Congenital Adrenal Hyperplasia	21-hydroxylase def (CYP21A)	United Kingdom - Glasgow RHC	...

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”).

Dashboard Add New Record Centre Records My Record List
Audit Trail

Beatrice Righi, Contributor Logout

> ADD RECORD

CONSENT (0/4)
required * 0/1

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

Require patient access

<< Back

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

CENTRE RECORDS

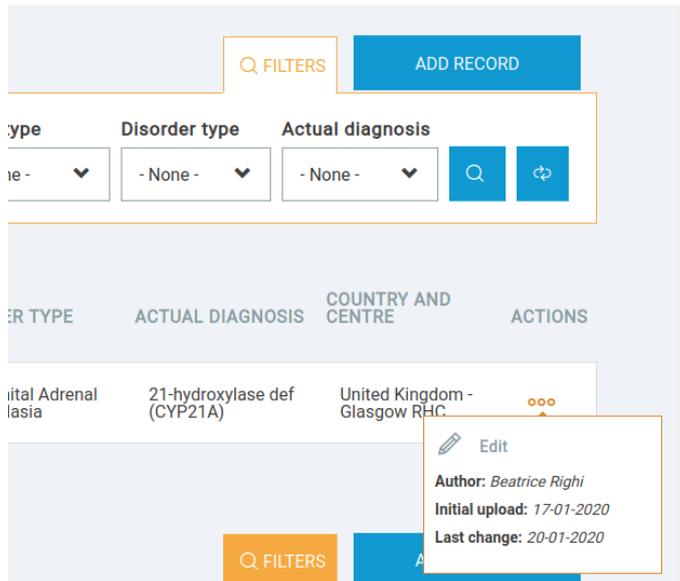
Q FILTERS ADD RECORD

Registry ID	Local ID	Year of birth	Karyotype	Disorder type	Actual diagnosis		
4599			- None -	- None -	- None -	Q	↺

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

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.

CONSENT (5/5)
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.

Can be contacted for research purposes *

No
 Yes

Data can be shared for research purposes

Yes
 No
 Not known

Require patient access

Patient's email

jillian.bryce@btinternet.com

View record audit trail

The record audit trail is visible by clicking the “History” tab;

Dashboard Add New Record Centre Records My Record List
Manage Users Audit Trail

Professor Mark Lanegan, Centre Lead 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 HISTORY

Responsible clinician: Professor Mark Lanegan Reg. ID: 1255 << Back

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

The screenshot shows the 'HISTORY' tab selected in the navigation bar. Below the navigation bar is a filterable table with columns 'Email', 'Date', and 'Operation'. The 'Date' column has a placeholder 'gg / mm / aaaa'. To the right of the filterable table is a 'FILTERS' button. Below the filterable table is a table with columns 'DATE', 'OPERATION', and 'LOG'. The table contains one row with the following data: '24-01-2020 13:44', 'update', and 'User peterpan (id: 9012) has updated Record having id 1255 (Record id: 1255)'.

Edit your profile

The screenshot shows the 'Edit your profile' page. At the top, there is a navigation bar with links: 'Dashboard', 'Add New Record', 'Centre Records', 'My Record List', 'Manage Users', and 'Audit Trail'. On the right side, there is a user profile card for 'Professor Richard Ross, Centre Lead' with a 'Logout' button. Below the navigation bar, there is a '> RROSS' link. The main content area contains a form with two fields: 'Current password' and 'Email address *'. The 'Email address' field contains the text 'r.j.ros63841@dev.kelyon.net'. Below the 'Email address' field, there is a small note: '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'. In the top right corner of the form area, there is a '<< Back' button.

A logged in user can edit all user data including:

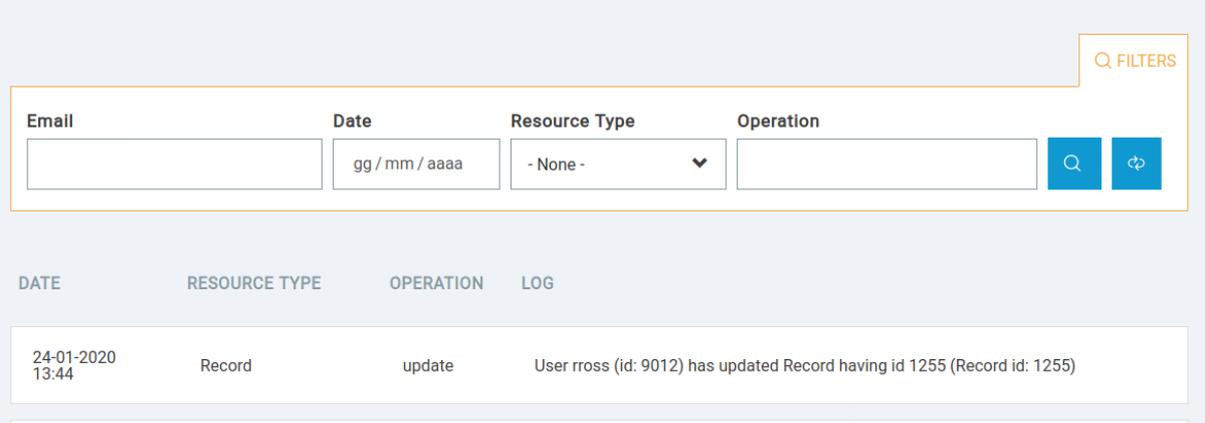
- Password
- Email address
- Full Name
- Phone Number
- Position
- Address
- Professional Society

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



The screenshot shows the 'AUDIT TRAIL' interface. At the top right, there is a 'FILTERS' button with a magnifying glass icon. Below it is a filter bar with four sections: 'Email' (an empty text input), 'Date' (a date picker showing 'gg / mm / aaaa'), 'Resource Type' (a dropdown menu showing '- None -'), and 'Operation' (an empty text input). To the right of the filter bar are two blue buttons: a search button with a magnifying glass icon and a refresh button with a circular arrow icon. Below the filter bar is a table with the following columns: 'DATE', 'RESOURCE TYPE', 'OPERATION', and 'LOG'. The table contains one row of data:

DATE	RESOURCE TYPE	OPERATION	LOG
24-01-2020 13:44	Record	update	User gross (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

 Nessun file selezionato.

 [Upload requirements](#)

*The fields with an asterisk are mandatory.

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.

Q FILTERS

Full Name <input style="width: 95%; height: 20px;" type="text"/>	Role <div style="border: 1px solid #ccc; padding: 2px; display: flex; align-items: center;"> - Any - ▼ </div>	Active <div style="border: 1px solid #ccc; padding: 2px; display: flex; align-items: center;"> - Any - ▼ </div>	<div style="display: flex; gap: 5px;"> Q ↻ </div>	
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FULL NAME	ROLES	ACTIONS
Nayananjani Karunasena	Contributor	⊘
Professor Richard Ross	Centre Lead	⊘
Eleni Daniel	Contributor	⊘