27.05.2020

Dear Registry Users

Launch of the new I-DSD/I-CAH platform
We are pleased to announce the launch of the new I-DSD/I-CAH registry platform. The url for the new registry remains as
https://registry.i-dsd.org/user/login

After the launch, the old registry will be available in read-only format at
https://registry-readonly.i-dsd.org/login.jsp

User manuals for using the new platform are available here:
https://home.i-dsd.org/new-platform/

Logging in for the first time
When you first login to the new platform your old login will not work. This is because there are stricter rules about your password. All you have to do to resolve this is click 'Forgot password?' and you will automatically be sent a new link to login with a new password.

You will also need to re-invite any patients that have previously been provided with access. I have the patient list with the IDs and can provide that to you to make this process easier.

New features
This has been a major piece of work for us and we are very pleased with the look and functionality in the new registry. There are also several new features that we hope you will find useful.

Some of the new features include:
- Additional consent levels for patients - sharing data for research, contact for research, patient access. If all 3 are checked, they will also be sent newsletters.
- Patients who have been provided access to view their own record (in read only format)
- Date of Birth - which will help determine actual age
- New data fields in the core information section - such as date of diagnosis, how diagnosis was reached
- DSD assessments - a longitudinal, age-specific tool for DSD
- Centre leads can approve new users in their own centre

Date of Birth
As we move to collecting DOB instead of YOB, all dates have been automatically set at 1st of January <YOB> - if you want this field to be accurate you will need to update these from your clinical records for the migrated data in the new platform; however, there is no urgency and this can be done in time when records are used in a study where there is a need for a DOB.

Data Migration

Data migration from the current registry has taken longer than originally expected. We have checked the data very thoroughly but due to the size and complexity of the registry it has not so far been possible to check every entry on every record. Therefore, when you do browse your own cases, if you find any inaccuracies please do let us know. The old registry will remain available in a read-only format at https://registry-readonly.i-dsd.org/login.jsp. If there any inaccuracies then we can help you manually correct these from the I-DSD/CAH Office; just let us know if you need help with this. There is one field 'associated conditions' which has not been migrated from the old registry and we can manually migrate this for you and will contact individual users about this. We have also noticed that there are some specific fields where there are occasional glitches – genetic diagnosis (certain/uncertain), lab results (rounded down rather than up), but do let us know if there is anything else.

Please do login and explore the new platform and send us your feedback. We are looking at additional functionality in the future and are receptive to all suggestions.

Any issues, please get in touch.

Kind regards