
How to upload your data to the IBD Registry

1.1 Introduction

In early 2022 we launched a new data access portal and consent process (where patients consent directly with the IBD Registry, **not** through their clinical team). This means you no longer have to record consents on your clinical system. It also means there is a different process for uploading your data to the IBD Registry.

There are 3 stages to data submission:

1. Extract your files from your system
2. Use the IBD Registry's [extract filter tool](#) to ensure only permissioned records are included
3. Upload data to the IBD Registry's data access portal

1.2 Extract your data from your system

The process of extracting your files from your system has not changed. Make sure you know where the IBD records extracted from your local system are saved on your computer or your hospital network.

1.3 Use the IBD Registry's extract filter tool

This is now an essential step when you submit records to us.

Our website provides [information about the extract filter tool and how to download it](#). There is a [guide](#) available, which you can access whenever you need a reminder about how to use the tool.

The tool takes the files extracted from your local system and removes any data that is not permissioned to flow to the IBD Registry. The tool does not change your original files – it produces new 'processed' files to save on your computer.

Get your files together

You will need:

- 1) The extract files that you produced in step 1
- 2) Your provenance file – this was emailed to you when you signed up for our data access portal.

You will need to update column C and D with the date and your name each time. Overwrite what is there already (do not add extra lines) and save it.

3) The list of consents (and withdrawals) for your Trust/Health Board. This only relates to new (version 4) consents, which we provide in the correct format for you to use, so all you need to do is download it. It is available from the new platform. To obtain this file:

- Sign-in to the [platform](#)
- Click on your Trust/Health Board name
- Click on 'consents (not uploaded)'
- Click on 'from Registry'
- Download the file that has 'no names' at the end of the file name and save this on your computer

4) For Trusts in England, you will also need a national data opt-out (NDOO) file

The file must be in a very specific format and must be a .dat file. Please see [separate guidance](#) on how to convert your file if needed.

If your hospital has a way of removing records for people who have signed the NDOO before extraction from your local system, then you should **untick** the NDOO compliance box in the bottom left corner. (This is because you do not need the tool to do anything to ensure that you are compliant because you have already done it.)

Otherwise, you should keep the box ticked and make sure that you have a NDOO file in the correct .dat format to load.

Once you have located all these files, you are ready to use the extract filter tool.

Process the files

- Import all of your files (see list above) into the extract filter tool import pane. You can drag and drop the files onto the file import pane or click the 'browse' button to find the files and load them.

If you have a lot of records, the tool may take a couple of minutes to process your files.

- You can make sure that all your files have been imported by checking there is a green tick in the corner of each of the file icons.
- Click the 'save output' button.

It should default to saving this folder within the folder of your original extract files. But you can choose to save it wherever you want.

- Once you have saved your files, you will have a folder called 'Processed' with today's date in the file name. The files that you will need to upload to the data access portal in the next step are now all inside this folder.

1.4 Upload files to our data access portal

If you are already logged in to the data access portal because you've downloaded your consent file, go back up to the top level.

If you have just [logged in](#), then click on your Trust/Health Board folder. If you are uploading for a specific hospital, then select your hospital folder.

- Click the 'add files' button
- Select the files that you want to upload – these are all the files that are in the 'processed' folder you created in the last step
You can highlight them all at once or use ctrl to manually select more than 1 at a time.
- Click open
- Check that all the files you need are there.
- Select the 'start upload' button at the top of the list to upload all the files in one go.
- Check all the files have been marked 'successfully uploaded' at the top of the page.

If you have any questions about the upload process or need any assistance, please email us at support@ibdregistry.org.uk