
Extract filter tool guide

Background

Clinical teams across the UK submit appropriately permissioned data to the IBD Registry. As the Registry upgrades its consent permissions, launches a new data access portal (containing the new data submission platform), and with the national data opt-out having been introduced in July 2022 (which overrides the s251 permission for hospitals in England only), it is important that clinical teams are assured that they are only submitting data they are allowed to send.

In January 2022, the IBD Registry launched a new consent process known as version 4 (V4). V4 permissioned data is allowed to flow to our new submission platform. Data that is consented using any previous version of consent (pre-V4) is not permissioned to flow to the new platform.

The IBD Registry has developed the extract filter tool (referred to in this document as “the tool”) to enable IBD Teams to ensure that only permissioned records flow to the new platform.

Purpose of the tool

To allow existing extracts from your IBD clinical tool (e.g. EPIC, PMS, WebTool, etc.) to be modified to allow submission to the IBD Registry’s new data submission platform.

From the existing extract files, the tool will:

- keep all version 4 (V4) consented records
- remove those who have withdrawn V4 consent
- remove pre-V4 consented records (which are only permissioned to flow to NHS Digital, not direct to the Registry)

The tool will also keep all records with no consent history, so that they can flow by the s251 permission. However, the tool contains optional functionality that will remove these records unless it receives specific instruction to keep them. This is the national data opt-out compliance functionality (applicable only for hospitals in England). This functionality will:

- remove records where no valid consent is in place and the patient has signed the national data opt-out, *providing the relevant file is imported (see full guidance below)*.

How it works

The files imported into the tool are checked for a valid consent record for each patient. If a valid consent record exists, the record is included; if an *invalid* consent record exists (i.e. a withdrawal or a pre-V4 consent only), the record is removed. If

there is no consent record present, then the record is included by virtue of s251 permission.

If you are at a hospital in England and your Trust has no other method of filtering the opt-outs from their s251 list, then the NDOO compliance box must be ticked. A .dat file of the s251 permissioned patients should then be imported (see full guidance below).

A chart that demonstrates this dataflow is in [Appendix 1](#).

Optional functionality: national data opt-out

The IBD Registry has s251 provision in place. This enables confidential patient information to be transferred to us without the Trust being in breach of the common law duty of confidentiality.

The national data opt-out allows patients in England to opt out of their confidential patient information being used for the secondary uses of research and planning. This means that their data may only be used for the primary use of individual care. For those who have opted out, their data is not permissioned to flow to us by the s251 provision.

The tool includes optional national data opt-out compliance functionality. By default, this is set to be on (the box is ticked).

Having this function switched on means, for data to flow to us by s251, you must upload a .dat file containing a list of patients who have not signed up to the national data opt-out (whose records are therefore permissioned to flow to us by s251). NHS Digital has a service called MESH that you can use to get this list. If you do not upload a file, but have this box ticked, the tool will remove any patients who have not consented to the Registry. That means no data will flow to the IBD Registry under s251 permission (which will have a knock-on effect on your Trust's quarterly reports and Quality Accounts).

If you do not want to use this functionality you can untick the box. This will mean that any patient that does not hold an IBD Registry consent record will be identified by the tool as being able to flow to the Registry under s251. You should only 'untick' this function if:

- your Trust is using an alternative method to remove patients from your clinical tool's extract files who have signed the national data opt-out.
- Your Trust is not in England

Before you start

Locate the files that you will need:

- the extract files from your IBD clinical tool
- national data opt-out file (England only)

- the most recent file(s) that the IBD Registry has sent you (containing Registry consents and withdrawals)
- your provenance file (sent to you by the IBD Registry and updated by you with your name and the date of submission, which will be needed when you make your submission to the Registry)

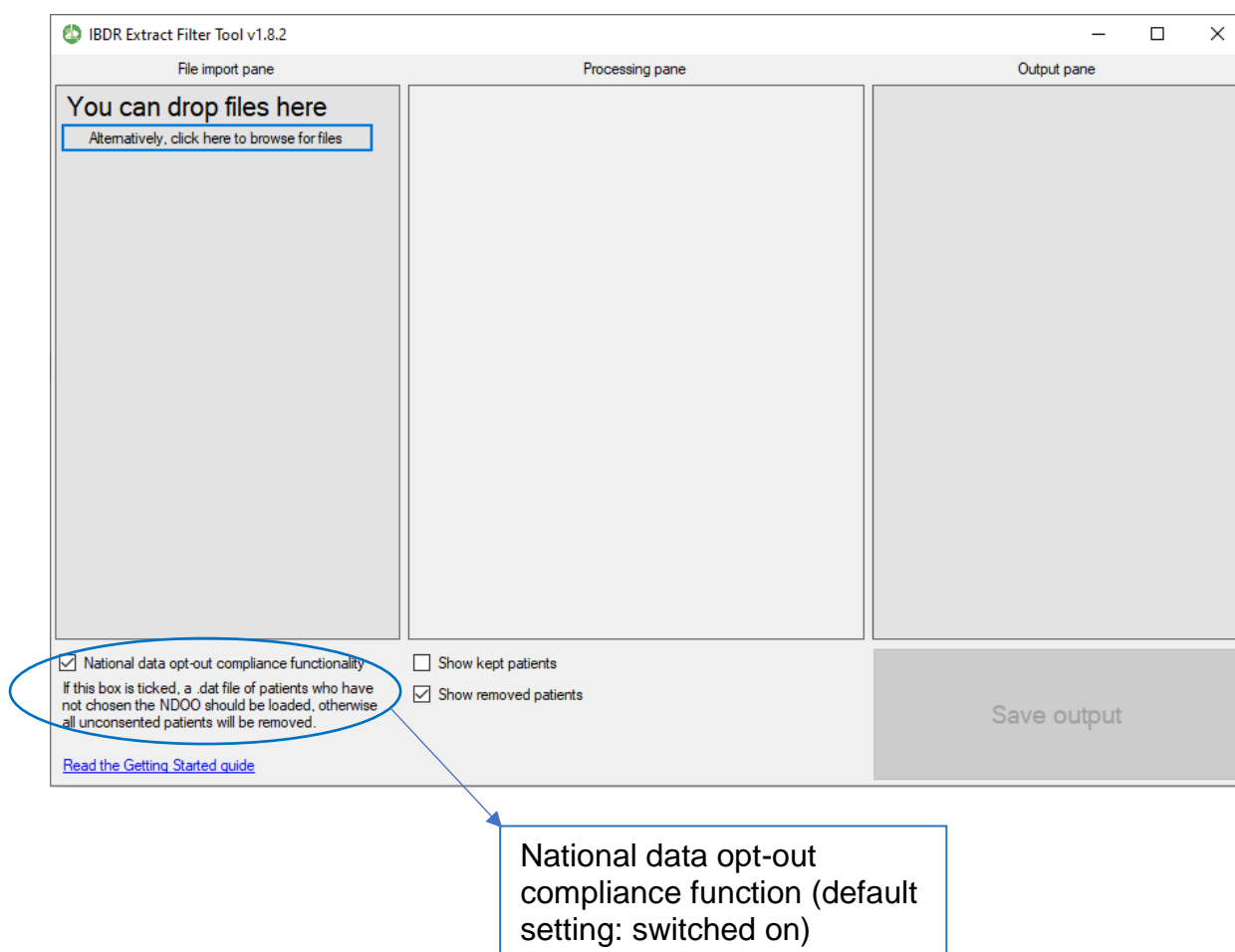
Tool overview

When you open the tool, you see 3 columns:

- a file import pane (where you import the files that you need to process)
- a processing pane (which summarises the actions that have been taken)
- an output pane (which shows a list of the files that are available to download from the tool)

Underneath the panes, there are tick-boxes so you can customise how the tool functions and what is displayed in the processing pane.

The save output button is in the bottom right, and is used to output your files once you are happy that you have successfully completed the filtering.



Importing files into the tool (file import pane)

The user can import files to the tool either by dragging and dropping, or by searching for the files in their file browser. Files can be dropped onto the import pane in any order. Files can be imported individually or a folder holding a set of files can be imported, however zip files will need to be extracted prior to import.

The user will need to import the following files into the tool. Please see [Appendix 2](#) for the requirements of each set of files. Please note, if the specifications are not met, the tool will not function correctly.

1) National data opt-out file – England only (please see section above regarding switching functionality on/off)

- Please note, this is a .dat file containing a list of patients who have NOT signed up to the national opt-out (i.e. a list of those patients whose data *can* flow by s251)

2) Extract files from your IBD clinical tool

3) File of consents and withdrawals provided to you by the IBD Registry via the data access portal (This will have the file name consent_[Trust name]_no_names.csv)

4) Provenance file

The files above can be imported to the tool in any order. The tool will automatically produce output files that have the correct permission to be submitted to the IBD Registry, based on the files that have been imported.

Please note that the tool will filter the files that are present, but does not check that all files that should have been imported have actually been loaded.

What the icons mean

When you load the files into the left pane, they will have an icon to the right of them.



File type recognised and loaded



National data opt-out file loaded



File type not recognised and therefore not loaded successfully

Please check that all the files uploaded are .csv files, with the exception of the national data opt-out file which should be a .dat file.

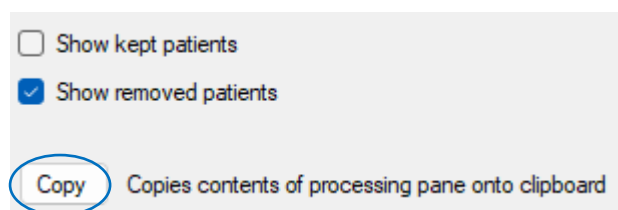
Processing pane

By default, the processing pane in the middle shows details of the removed records. If you click the arrow on each record it will show further details and the reason they have been removed.

You can use the tick boxes below the processing pane to set the tool to show the records that have been kept, the records that have been removed, or both.

In extract filter tool version 1.11.1 onwards, at the bottom of the screen there is the option to copy the contents of the processing pane.

This will allow you to obtain a list of the NHS numbers that featured in the original files, but have been removed from the output files (providing the 'show removed patients' box is ticked). You may wish to target those patients to sign up to the Registry's consent form.



Clicking copy will then allow you to paste the contents of the processing pane into another program (we recommend Excel).

How to access your filtered files

The processed files will be visible in the output pane. These are the files you will need to upload to the IBD Registry's data submission platform.

The output pane will contain a list of the files for you to download and a list of files that have been excluded. Any files that are empty post-processing will be excluded from the output list. This means that the number of output files may be lower than the number of input files. This is not an issue: the upload to the platform will still work providing, as a minimum, the patient file and provenance file are both present. If you have loaded a national data opt-out file this will always show in the list of excluded files, as it is not uploaded to the Registry.

Output pane

biologicsevent_Pr...	1 records kept 6 records removed
contact_Process...	6 records kept 19 records removed
diagnosis_Proces...	3 records kept 5 records removed
medication_Proc...	2 records kept 9 records removed
patient_Processe...	3 records kept 5 records removed
consent_Process...	5 records kept 40 records removed
provenance_Pro...	No patient records in file

7 files were excluded from the output:
 -Admission.csv
 -Cancer.csv
 -Growth.csv
 -IbdImpact.csv
 -PromControl.csv
 -Surgery.csv
 -optout_v1.6testing.dat

Save output

Your provenance file will show in the list of output files but will be marked with “No patient records in file”. This is to be expected.

Once you are certain that you have loaded all of the required files, click on the ‘save output’ button at the bottom right of the screen.

The default location for the files to be saved will be within the folder where most of your imported files came from (this is likely to be the folder of extract files from your clinical system). It will not overwrite your original files, but create a new folder containing the processed files. You can browse your computer to save them elsewhere if you wish.

The output folder will be named Processed_[date]. The files within the folder will all end in _Processed. This is to help ensure that you upload the correct files to the data submission platform.

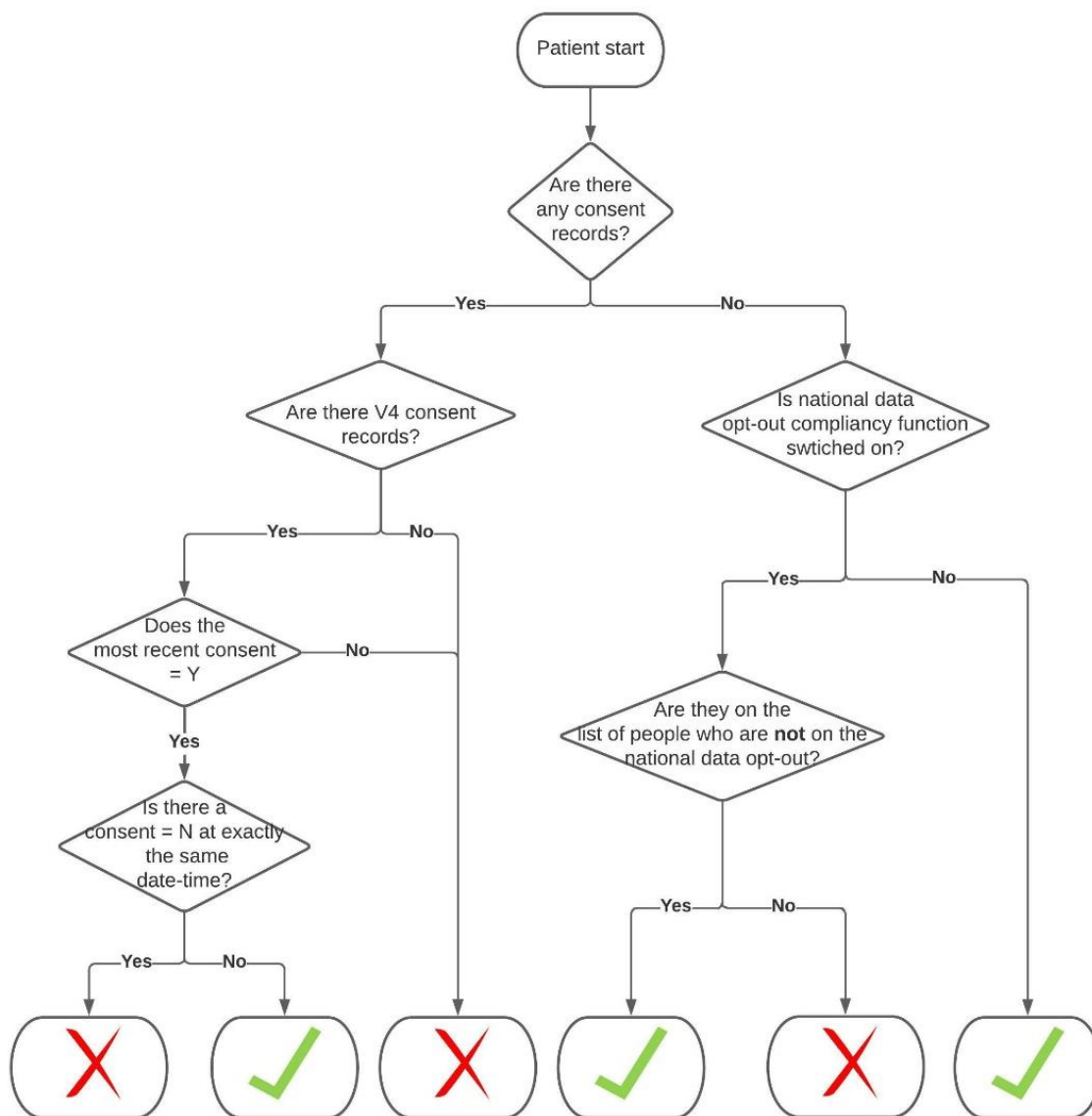
If you spot anything unusual in the files after processing, please do not make changes to the processed file. Please contact us explaining your concerns before submitting the file: support@ibdregistry.org.uk (please do not include any patient data in your email).

Submit the files

You should upload your output files (those files whose name ends _Processed) to the IBD Registry’s data submission platform which is accessed through our clinical data access portal.

If you have any queries, please contact support@ibdregistry.org.uk

Appendix 1 – logic for the tool



Appendix 2 – file specifications

National data opt-out file (please see section above):

- a list of NHS numbers of patients who have NOT signed up to the national data opt-out (i.e. a list of those patients whose data *can* flow by s251)
- a .dat file (it can be named anything, but the file extension must be .dat)
- the list of NHS numbers must be separated by commas and carriage return or just a carriage return

(If your Trust provides you with a list of NDOO information in a different format to above, please see our [separate guidance](#) on how to convert your file into the format above so that it can be used in the extract filter tool.)

2) Extract files from your IBD clinical system:

- must be in a format approved by the IBD Registry for submission (e.g. 2015_H, 2019_J or 2021_K format)
- should include the consent file, the name of which must begin with “Consent”
- be the file type .csv

3) Consent list from the IBD Registry:

- a list of patients, provided to you by the IBD Registry, that have a V4 consent record (must be loaded in the exact format that it was sent to you)
- if there are no patients with a V4 consent record then no file will be present
- called “Consent_...”
- be the file type .csv

4) Provenance file

- The provenance file (sent to you by the IBD Registry)
- File name must start with the word “provenance”