

BTS UK Interstitial Lung Disease Registry Quick Start Guide for Registry Users

The BTS UK ILD Registry website can be found at: <https://registry.brit-thoracic.org.uk/>.

Criteria for inclusion

Patients may be included if they meet all three of the following criteria:

- First seen for the first time in clinic at the participating centre from 1st January 2013.
- Patients with a new or historic diagnosis of either:
 - any ILD with evidence of fibrosis, including definite or strongly suspected IPF, OR
 - any sarcoidosis with pulmonary involvement, with or without fibrosis.
- Informed, written consent has been obtained.

Obtaining consent

Consent must be written, and patient consent forms are available *Document Library* button on the Registry home page, along with a template cover letter for forms which are posted or emailed to patients. Consent may be either a 'wet ink' signature or remote consent, in line with the *2018 MHRA/HRA Guidance on the Use of Electronic Consent*.

Using the standard consent forms, remote consent will be considered valid if patients:

- Email the clinic an electronic copy of a signed form (scanned, photographed, etc.), or
- Email the clinic a form with their signature typed in.

Whichever method is used for consent the signed form should be retained in the patient notes, with one copy given to the patient and one to the site's Registry Lead (to be retained in the site file).

When are data collected?

For each patient whose details are added to the Registry there are three types of data to upload:

- Demographic data - Entered once for each patient.
- Diagnosis/clinical information data - Entered once for each patient. Details relate to the time of first presentation to the clinic.
- Follow-up data - Entered at each follow-up clinic visit (ideally every twelve months, but all follow up entries are gratefully received).

Data collection sheets, which can be used to make notes before data entry, may be downloaded through the *Document Library* button on the Registry home page.

Adding a new patient to the Registry

The Registry home page includes a number of large menu buttons. Selecting *New Patient* will open a new demographic record into which data may be entered. You may save entries on this screen and return at any time to complete data entry.

When a new patient is added online they are automatically assigned a unique Patient ID. Every record attached to that patient (such as follow up records) will also have a unique Submission ID. **BTS staff can only locate individual patient records using this unique Patient ID.**

Automatic duplicate check - When a new record is saved a check is automatically made for duplicate entries. If matches are found the record cannot be saved, and an error will appear giving details of which hospital the patient is listed under. If the record should be transferred, please contact BTS.

Amending an existing record

From the Registry home page select *Existing Patient*. This will open up the *Patient List* page, where the relevant patient can be selected by clicking the *Open* icon on the right.

This will open the Patient Home page. From here select either the *Diagnosis* or *Follow Up* button to enter information relating respectively to the first clinic visit or to any subsequent follow up visit. Demographic data may be amended at any time by selecting *Edit Patient Demographics* just above the table at the top of the page.

The table in the *Patient List* page includes an estimated next follow-up date for each patient. This is twelve months from the date of the last clinic visit recorded for that patient.

Committing records

Clinical information and follow-up records must be committed – i.e. locked – to be included in reports and analysis. **Demographic records cannot be committed**, as details about name, post code or date of death may need to be updated.

The *Status List* button on the Registry home page leads to a list of all submissions made by your institution. Records may only be committed when valid, meaning all required fields (marked with a red asterisk when entering data) are complete. When a record is valid a green cross will appear in the *Commit* column. Clicking on this green cross will commit the record.

The *Status List* page also allows users to delete records by clicking on the red cross in the *Delete* column. Please note that deleted records cannot be recovered.

If a user needs to make an amendment to a committed record, a request to uncommit (unlock) that record may be sent the BTS Head Office by opening the submission and clicking *Send request to site administrators to uncommit this submission* under the table at the top of the page.

Other useful information

1) What to do if a patient withdraws their consent to participate

If a patient withdraws their consent to be part of the Registry, please notify BTS Head Office with a request to delete all records associated with that patient ID from the Registry database.

2) How to record if a patient has died

If a patient has died please edit their demographic record to reflect this. Please also tick the box at the bottom of the Patient Home page to indicate that follow-up email reminders are no longer required.

3) Exporting data for all patients entered at your hospital

All users are able to export their hospital's full dataset to a spreadsheet for local use/analysis. Select *Data Export* from the Registry home page. On the Export page use the dropdown menus to select which data to export (e.g. demographic) and which records to include (committed, open i.e. unlocked, or all).

4) User-downloadable reports are available through the Registry site

Select *Statistics/Reports* from the Registry home page to access the reports which are currently available. Select the 'Run' icon to download the report of your choosing.

5) NHSE ILD Quality Dashboard reports are available to all users

This report relates solely to cases of IPF, and users must select reporting period dates at the time of download. Although only English specialist centres are required to submit these returns to NHSE, all other centres across the UK may use this report for benchmarking and local monitoring.

TIP: Sorting tables

Click on the title text of any column to sort the table by that field.

TIP: Committing or deleting

Records **must** be committed to be included in local dashboard returns, reports and national data analysis.

Use the *Status List* page to commit or delete records as needed.

Instructions for Spreadsheet Data Upload Function

The Data Upload Function is an extra tool which gives users the option of uploading data for multiple patients onto the Registry directly from an Excel spreadsheet. This is a three-step process, and it may only be used to add new records (e.g. adding a new follow-up record for a patient) **not** to partially completed records.

Step One: Export a template spreadsheet

- 1) From the Registry home page, select *Data Upload Function* and then *Export*.
- 2) Select the type of data you will be entering, then:
 - To enter demographic data for new patients, select the number of records to export (i.e. the number of new records you intend to create).
 - For all other records select the number of records required, then select the specific patients you wish to add records to from the list provided.
- 3) Click *Export to Excel file*.

TIP: Demographic records first

A patient may only be included in clinical information/follow-up templates if they already have a demographic record on the Registry. So if you use this function the demographic information will need to be uploaded **before** those patients are included in the other exports.

PLEASE NOTE: Each downloaded template is unique and matching blank records are automatically created on the Registry site at the time of download. This means each unique template spreadsheet that is downloaded may only be uploaded to the site **once**.

It also means that the blank records remain on the site regardless of whether or not the spreadsheet is used to populate them. Blank records that are created but not populated may always be deleted from the site through the *Status List* page.

Step Two: Populating the spreadsheet

Data should only be added to cells which are highlighted in blue. No data should be added to white cells.

Where users may select multiple answer options for a single question (e.g. HRCT features) every answer option is listed in the spreadsheet. For these questions users should select *True* for options which do apply and leave all other options blank.

You can save the spreadsheet and add data at intervals but please note that no new fields should be added and data should only be added alongside pre-populated patient ID, or the system will reject the data.

TIP: Freeze panes in Excel

The spreadsheets are large, so use the *Freeze Panes* function in Excel to ensure the questions and patient identifiers are always visible.

Step Three: Uploading data to the Registry system

After the template spreadsheet has been populated with data it may then be uploaded onto the Registry. Uploading the spreadsheet automatically populates fields in the blank records that were created in the system at the time the template was exported. To upload the data:

- 1) From the homepage, select *Data Upload Function* and then *Import*.
- 2) Click *Choose File* and select the spreadsheet that has been populated with data.
- 3) Click *Import from Excel file*.
- 4) When the upload is complete, please check all records are correct by opening the *Status List* page and opening/checking each of the newly populated records.
- 5) When clinical information and follow up records are confirmed to be complete, please commit them.