

# UK Cystic Fibrosis Registry

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## *User guide*

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Updates: Dashboard section expanded

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# Introduction

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Welcome to the new UK CF Registry system, launched on 1 February 2016. Please read this user guide, particularly the key FAQs below, before entering data onto the new system, and refer to it frequently as you familiarise yourself with it. We will update this user guide in line with queries we receive, and as we develop the system further.

## FAQs

### **Why doesn't my username work?**

Your username is now your NHS/Academic institution email address.

### **Why does historic data look incomplete?**

All data from PortCF that has been migrated into the new system will appear 'incomplete'. This is because the new system has a slightly different data entry procedure and we couldn't 'make up' data for historic entries to force these historic records to look complete

1. Demographic data: As you enter data for each patient please check the three tabs in this section, and update any missing data so that all tabs are 'green'. This should take one minute or less per patient. All demographic sections should be 'Green' and 'Complete' by the 2016 data entry deadline
2. Annual review/Encounter data: 2015 data and earlier data are locked and cannot be edited. The fact that these records appear 'incomplete' will not factor in to banding calculations or analysis – anything that was complete on PortCF will be used in analysis as in previous years

### **Where is the Annual survey form?**

The PortCF Annual Survey form has been combined with the annual review encounter, so the mandatory dataset for 2016 will be one annual review encounter, and the patient's demographics.

Annual review encounters require the full dataset to be entered, whereas other encounters' requests minimal data only.

### **Where is the Care episodes form?**

Care episodes were previously collected in two places, the Care episodes form, and the Annual Survey form. These data are now collected in Encounters only.

### **How do I record shared care?**

When adding a new patient select the site they are usually seen at, and click 'Add new'. The system stores the CF network information, so if you add a patient under their clinic, the system 'knows' which centre this clinic is attached to.

In the 'Core information' tab in an encounter, select 'shared care' and then indicate where the patient was seen. This allows for scenarios where a patient is normally seen as their

clinic, but goes to the CF centre once a year, or is seen near their university for some appointments.

### What data items have been changed?

Although the data entry forms have been changed to be more user friendly, most of the data variables are the same in the new system as they were in PortCF. A larger dataset enhancement is planned for 2017. There are a small number of exceptions, outlined below.

A significant number of fields, such as Chronic Medications, are now automatically populated based on previously entered data. For more information about how we've improved data entry, see the 'help' icons next to variables in the system, and the Entering data [sections](#) below.

**All historic data**, exactly as it appeared in PortCF, can be accessed via the Registry team if required. Depending on demand this will be made available to all users. If you wish to continue collecting any retired fields, you can add the question as a [custom field](#).

### Retired PortCF fields

1. Biological paternal heights
2. Socio economic status of parents
3. Duplicated CFRD fields have been merged

### Fields now auto-calculated

1. Hospital IV days
2. Home IV days
3. Non IV hospital admissions days
4. Best FEV<sub>1</sub> data (if entered in prior encounters)

### New Registry system variables

1. PolyT status (where relevant)
2. Encounter setting
3. Liver test detail

# Your account

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## Logging in

The UK CF Registry portal can be found at <https://cfregistry.org.uk>. When logging in you will be asked to confirm agreement with the Registry terms of use. Please read these carefully before proceeding.

The first time you log in you need to click the link shown below to set up your password, using your institution's email address as your username:

### Login

Please enter your login details...

Username:  \*

Password:  \*

Need to set your password or forgotten your password? [click here](#)

Forgot your user name? Please contact CF Registry Team:  
Email: [registry@cysticfibrosis.org.uk](mailto:registry@cysticfibrosis.org.uk)  
Telephone: 020 3795 2180

## Setting or re-setting your password

To set your password for the first time, or re-set a forgotten password, you will need to have first been set up as a User by your Site Administrator or the Registry Team. Your username should your NHS or academic institution email address.

When logging in for the first time, click the link after 'Need to set your password or forgotten your password?' on the home screen.

On the password request screen enter your registered email address. The system will generate a unique code, which will be emailed to you. Click the link within the email and enter your code to set your password.

## Two-factor authentication

The Registry uses two-factor authentication to protect patient data (similar to logging in to online banking). When logging in for the first time from a new web browser, you will be asked to retrieve and enter a verification code. A code will be sent to the email that acts as your username. Once you've received the code, return to the site and enter it to login. You can opt to remember your browser to avoid having to repeat this process next time you login. If you don't receive your code within 5 minutes, check your Junk and/or Clutter folders. If you still haven't received your code, email [registry@cysticfibrosis.org.uk](mailto:registry@cysticfibrosis.org.uk).

**Registry users sharing a computer:** For security purposes two-factor authentication is re-set when Registry accounts are switched using the same browser on the same PC. So, Registry users sharing a computer may have to repeat the security code process after the other user has been logged in.

## My profile

Using the 'My profile' menu, you can amend your email address, password, and telephone number. You can also see which cystic fibrosis sites you have permission to access.

## User types

### Site administrators

Site administrators are responsible for managing the Registry access for their CF site. They can **add new users** with the appropriate permission level, and must **disable users** when they no longer require access to the system. Site administrators are the only users authorised to set up [custom fields](#) and access their site's [audit log](#).

Site administrators are also responsible for responding to requests from the Registry team for periodic **User audits**; confirming which users still require access to their site(s). Failure to respond to these requests within the given time period will result in access to the Registry being revoked for all site users until a response is received.

### Setting up new users

To set up a new user, it is important to establish the level of access required, always applying the minimum required with reference to the user roles detailed in this section. You can only assign user permission levels that are equal to or lower than your own, so some options (such as CFT administrator) will be disabled.

1. To set up a new user, go to the 'User management' menu, and select the 'Add new' button.
2. Enter the email address (doubles up as a username), which must be a valid NHS or academic institution email address
3. Enter the user's full name (first name and surname)
4. Select the 'CF sites' radio button to tell the system you are setting up a new site user
5. Against the site(s) that you wish the user to be able to access (you will only see the site(s) you have access to) select whether they should be a Site Administrator, Site Editor, or Site Reader. You can select different permission levels for the same person for different sites
6. Click 'Insert' to save your changes. The new user can now select 'Need to set your password' on the login screen and use their email address to set a password and access the site

### Editing users

To edit a user's details or permission levels, find the user in question (note: you can 'sort' users using the column headers), and click the pencil edit icon to the right of their details. From there you can edit all of the details entered at the time of setting up the user. Remember to click the 'update' button prior to moving on to save your changes.

### Disabling users

To disable a user, who may have moved onto a new role or left the CF site, simply click the recycling bin icon to delete their profile.

### **Site editors**

Site editors are able to edit unlocked data, add new encounters, annual reviews, and patients. They can also transfer patients, view reports and the event log, query, and export data.

### **Site readers**

Site readers are able to view all data for their site, but they cannot edit data within the system. They can view reports, query and export data.

### **Event log (Audit log)**

Site administrators can use the Event log to access an overview of actions relating to data at your site. This includes user activity and data edits. You can also search for specific events, event types, and date ranges.







# Managing patients

## Record management screen

This is the patient data home screen; from this screen you can view the completeness of individual patients' data, search for patients, add new patients, and enter data.

## Colour coding

Completeness of data is represented using the following colours:

 Complete	Tabs and records that are saved as complete.
 Incomplete	Saved with some but not all mandatory data complete
 Errors	Saved but with errors, such as invalid dates or information in the wrong format
 Not saved	Tab/encounter hasn't been opened and saved

## Search for a patient

You can search for a patient using their CFTID, first name, surname, date of birth, or NHS number using the box at the top right of the patient management screen.

## Advanced search


As well as the standard search, you can use an advanced search to locate a patient, or group of patients.

## Add a new patient

Before creating a new patient, always search to ensure that they do not already exist for your centre. A patient from another UK CF centre will normally already exist on the Registry under their centre of origin.

To add a new patient, first select the name of the CF site *where the patient receives care* (if they receive care at a clinic, select the clinic, not the CF centre), then click 'Add record'. The system will flag if this patient might be a duplicate in the system based on the details that are entered as their demographics. Before overriding this alert, consider whether this patient may already exist, either in your CF care network, or whether this patient may be listed under another centre and has not yet been [transferred](#).

## Patient transfers

When a patient permanently transfers out of your CF site, you should transfer the patient's record to the new site by clicking the  button on the record management screen.

If a patient is being seen at another clinic as a 'one off' or on a temporary basis (e.g. if at University), record this in the ['core information'](#) tab in the relevant encounter rather than transferring them.

For data protection reasons, you cannot search for a patient who has moved to your CF site, but has not yet been electronically transferred by their previous care team. Please contact [registry@cysticfibrosis.org.uk](mailto:registry@cysticfibrosis.org.uk), who will arrange the electronic transfer. Do not include any patient identifiable data in the email, you will be provided with instructions.

## Duplicates

The system will prevent duplicate records being created by validating unique information against all other records held on the Registry. However, if you notice a duplicate patient record has been created, please contact [registry@cysticfibrosis.org.uk](mailto:registry@cysticfibrosis.org.uk) and provide the CFTID of both patient records.

## Entering data

### Error messages

When you click save on a data entry form, a colour coded bar will appear at the bottom of your browser window.

Green	No errors – saved complete
Amber	Errors or incomplete fields
Red	Saved with errors, for example blank mandatory fields or answers that contradict validation rules


If an error bar displays, the questions with errors will be highlighted with explanatory text e.g. 'Required', if the field is mandatory, or 'Must be after birth'. You can quickly skip to relevant fields by clicking 'show errors' in the coloured bar at the bottom of the screen and then selecting the question references that appear.

### Demographics

Demographic data is always associated with an individual patient, even if their care moves from one centre to another. It isn't locked as part of the annual reporting cycle, and can always be updated.

A complete demographic record must be available for every patient in order for that patient's data to be included in tariff payment calculations, registry grant payments, and the annual report.

Demographic data, even if it looks complete, should be checked for each patient at least once per year to ensure all information, like surname, and postcode, are accurate and up to date.

To read or edit demographic data, click on the  button to the right of the patient's name on the record management screen.

## Patient information

### Consent

When creating a new record, or accepting a patient transferred from another CF care team, the Registry now asks you to confirm that written consent has been taken for that patient. This is designed to act as a reminder to check that written consent is available at your centre

for this patient. This is not a field that will be analysed by the Registry team, and copies of consent forms on-site are part of the criteria for passing a UK CF Registry validation visit.

Changing a patients' consent status to 'No' will make all data associated with that patient read-only, and prevent further data being added. It will also send an alert to the Registry team, who will be in touch to ascertain:

1. Whether the patient has withdrawn consent from the UK CF Registry
2. Whether the patient consents for historic data to be retained
3. Whether the patient wishes for no further data to be collected **and** all historic data to be deleted

## Genotyping

Genotyping data for at least two mutations should be present for every person on the Registry. Although users are allowed to indicate that a patient has not yet been genotyped, these incomplete data will appear on in-system reports as well as being chased by the Registry team.

Up to three mutations be selected, and you can search for genotypes by starting to type the mutation name in any of the three nomenclatures. In 2016 for the first time the Registry has begun collecting data about another part of the CFTR gene, called the poly-T tract. The poly-T tract occurs in one of three forms; 5T, 7T or 9T. The Registry will automatically show poly-T tract status options where its form may affect the CF outcome.

## Diagnosis


This tab collects information about when and how a patient was diagnosed with cystic fibrosis. It also collects outcome data about life status and diagnosis reversal; these sections can be left blank if they do not apply. If life status is recorded in an encounter it is automatically updated in the diagnosis section.


## Encounter

An encounter applies to any event where a patient is assessed by a cystic fibrosis care team. This could be an outpatient, inpatient, or virtual appointment.

You can also record scheduled visits that did not take place because a patient did not attend, or has been transferred to another centre.

Encounters are not mandatory data for the UK CF Registry, but completing them throughout the year will auto-populate annual review data, and enable you to get better feedback about care at your CF centre.

You can find guidance about individual questions in the Encounter forms by clicking the  icon to the right of the data entry form on the UK CF Registry website.

To create an encounter, click the  icon next to the left of the patient's name and click 'add encounter'.


## Annual review encounter

An annual review encounter is a more detailed set of data than a normal encounter. It is mandatory to enter one annual review encounter for each 'active' consenting cystic fibrosis patient each calendar year. These data are used for tariff payments, centre grant payments, and the Annual reports.


If encounters have been entered throughout the year, some data within the annual review encounter will be automatically populated in the annual review encounter. Autocompleted data should always be carefully checked and edited / added to if necessary to accurately reflect patient care.

An annual review should be carried out when a patient is 'well' i.e. not having an exacerbation.

If a patient has not had a "formal" annual review in the period then a "virtual" review must be recorded from the patient's notes. The virtual review must be compiled from a time when the patient was stable during the period.

You can find guidance about individual questions in the Annual review forms by clicking the  icon to the right of the data entry form on the UK CF Registry website.

Note: In PortCF the mandatory dataset for the year included Annual Survey, Annual Review Encounter, and Admission and Care episodes. In the new Registry these forms have been combined in the 'Annual Review'. This must be completed in its entirety to constitute the minimum data for that year.

To create an annual review, click the  icon next to the left of the patient's name and click 'add annual review'.

## Core information

This is the default tab you are brought to when entering an encounter. It primarily collects information about the encounter itself, as well as some core information about the patient.

If the patient is shared care, indicate this here. You can then record where the patient was seen for the encounter you are recording. For example a patient may generally receive care at a clinic, but be seen occasionally at the CF centre. You can also use this function to record when a patient is seen at a clinic near their university, for example, but hasn't been permanently transferred to their university centre.

## Admissions & IVs

If there are no admissions or IVs to report, select 'None' in the three dropdown menus and move on.

Admissions and IVs from encounters throughout the year auto-populate the annual review encounter; so, entering them as you go along makes things easier at year end.

If in an annual review encounter you find that one or more admission or IV episode is missing, you can edit what's there to make sure your records are complete.

## Investigations

Entering FEV data throughout the year will automatically populate the 'Best FEV1' field in the annual review encounter. If you know a better FEV1 has been recorded in clinic but not on the Registry, this field can be amended to reflect this.

In an encounter you can choose to add in investigations that are additional to the core data items, such as CFRD screening. In an annual review an answer to all of these questions is required to ensure complete data capture.


## Chronic medications

Chronic medications are therapies that the patient has been prescribed for three months or more, including vitamins.

Chronic medications are carried through from encounter to encounter, and annual review to annual review, until a user records that the patient has stopped taking the drug.

This means that, after the initial visit, medications are reviewed and edited where necessary, but do not have to be entered anew each time.

To add a new medication click the '+' icon and start typing the medication name to select it. The drug type will be automatically selected but can be amended if necessary using the 'other' option – this will help us to improve our coding.

Always remember to click  when you've finished entering medication data to ensure that it is saved. Once you've added them all, click 'Save' at the side of the screen before moving on.

## Culture & microbiology

Detailed culture and microbiology data completed in encounters throughout the year autocompletes the aggregate microbiology view at annual review. If it is not realistic to enter this level of detail in an encounter, record that no microbiology data are available and simply enter the aggregate data in the annual review. Detailed data are not required at annual review as it is not expected that this will be available or practical to collect if it has not been recorded during the course of the year.

NTM data are collected in this tab at annual review only.

## Complications

This tab is designed to collect information about short and longer term complications. Long term complications will carry over from one encounter to the next. Selecting 'yes' to a complication will open up additional fields about that complication.

## Nutritional assessment

This tab is designed to collect nutrition and growth data.

## Physio

The physiotherapy tab collects airway clearance, exercise test, continence and posture data.

## Lifestyle

This tab is only required at annual review. It collects information about smoking, and pregnancy.

## Outcome

This tab is only required at annual review. It collects information about death, diagnosis reversal and transplant. If a user indicates death and diagnosis reversal has occurred this auto populates data in the demographic record for that patient. Reversing a diagnosis or marking a patient as deceased alters a patient's record to 'inactive'.

## Custom fields

To help your clinic or centre capture additional data on patients that is useful to you, but not included in the current data set, the Registry provides **Site Administrators** with the capability to create custom fields that are unique to anyone with access to your site. This might be for the purposes of a local or service evaluation or clinical audit. If another user wishes to set up a custom field they should contact their Site Administrator.

Custom fields are automatically added to both encounters and annual review encounters, but by not selecting the 'Required' option this field will not be mandatory and can be completed only when required locally.

If you wish to undertake regional data collection but do not have access to all of the sites involved please contact [registry@cysticfibrosis.org.uk](mailto:registry@cysticfibrosis.org.uk) for advice.

Although data within custom fields won't be analysed centrally, please be aware that both the questions and the data within them can be accessed by the central Registry team. This is so that we can identify trends in centre requirements with a view to keeping the national dataset as relevant as possible.

## Setting up a custom field

From the home screen, go to Patients > Custom Fields

You will be presented with the Custom Fields screen.

1. Select the site that you want to add the custom field to from the 'Team' drop-down:
2. Click the (+) next to 'Add custom field'

You'll be presented with a data entry screen:

Id:	To be assigned
Identifying code (optional):	<input type="text"/>
Question No.:	<input type="text"/> Auto
Text:	<input type="text"/>
Type:	[Please Select...] ▼
Required:	<input type="checkbox"/>
Active:	<input type="checkbox"/>
Indent:	[Please Select...] ▼
	<input type="button" value="Insert"/> <input type="button" value="Cancel"/>

*Id:* Will be automatically assigned by the system when saving your new field. The field will be referred to using this number in the [Query builder](#).

*Identifying Code:* Not mandatory, but can be added to help you manage your custom fields on this screen. This will not be shown on the data form.

*Question No.:* Set your own numbering or tick 'auto' to allow the system to number your questions sequentially.

*Text:* Type your question or data label here – this is the text that will appear on the data entry form. You can make this title as long as you like. However, if want to include instructions for the question, you may want to consider putting this into a header (see below) with the question underneath.

*Required:* If ticked, the question will require an answer in order to save the 'custom fields' tab as complete

*Active:* Select this if/when you want to make the question 'live' on the site. If you ever want to stop asking a custom question, you can deselect 'active' to make it dormant. It's a good idea to deactivate rather than delete historic custom fields, in case you want query the data or reuse the question.

*Indent:* A formatting option that moves text towards the right side of the form. You may want to indent sub headings or questions underneath a heading.

*Type:* Use this drop down menu to define the type of field you wish to create.

- **Header:** Can be used as a section title, or for user instruction before the data field itself.

The screenshot shows a navigation bar with 11 tabs: 1. Core Information, 2. Admissions & IVs, 3. Investigations, 4. Chronic Medications, 5. Culture & Microbiology, 6. Complications, 7. Growth & Nutrition, 8. Physio, 9. Lifestyle, 10. Outcome, and 11. Custom fields. Below the tabs, the 'Custom fields for this Team' section is active. It displays a field with the ID '11.1.1' and the text 'This is a Header' in a bold font. On the right side of the interface, there are 'Save' and 'Exit' buttons.

- **Bold Text:** This can also be used as a label or a sub-header if required.

This screenshot is identical to the previous one, but it shows two fields. The first field has ID '11.1.1' and the text 'This is a Header' in bold. The second field has ID '11.1.2' and the text 'This is bold text' in bold. The 'Save' and 'Exit' buttons are visible on the right.

- **Text Box:** Use this if the question requires a free-text response. There are extra fields required to set this up:

The screenshot shows a configuration window for a question. The fields are as follows:

- Id:** To be assigned
- Identifying code (optional):** AA3
- Question No.:** auto (with a checked 'Auto' checkbox)
- Text:** Text Box
- Type:** Text box (dropdown menu)
- Width (px):** 123
- Rows:** 3 (dropdown menu)
- Required:**
- Active:**
- Indent:** 1 (dropdown menu)

At the bottom of the configuration window are two buttons: 'Insert' and 'Cancel'.

- **Width (px):** This governs how far across the page the text box will stretch across the page
- **Rows:** How many rows the text box will take up on the page
- **Radio button list:** This sets up a question where all options are displayed as a list, and one option can be selected as an answer. To set up a radio button list, select this option, click 'insert' at the bottom of the page, and then click 'edit' to add your list items.

To add responses, click the (+) next to add option. You will need to enter a description (what the user will see on the form) and a value (what will be held in the database). The Value would normally be ascending numbers (answer 1 = '1'). When using the query builder or exporting this data, you will see the value rather than the option description, so ensure that you can work with the values you choose. Select 'update' to save these additions.

*Align:* You have the options of aligning the radio buttons either vertically (one underneath the other) or horizontally (one to the right of the other).

- **Drop down list:** Set up a drop-down list in the same way as the radio buttons above, but this will display in a list that is expanded when the user clicks into the field to make a single selection.



- **Numeric:** A question where the answer is always a number. You can add the validation rules below to help collect accurate, error free, data:
  - **Decimal places:** Set the number of decimal places, if any, the answer may be in (0, 0.1, 0.12 etc.)
  - **Minimum value:** If this is set, any value less than this that the user enters will cause an error. This can include negative values



- **Maximum value:** If this is set, any value greater than this that the user enters will cause an error
- **Date, Time, and Date / Time:** Use when the answer will always be a date (DD/MM/YYYY) and/or time. For questions including a date the user will use a calendar pop-up to answer the question. Future dates, or dates before 01/01/1900 cannot be selected
- **Check boxes:** Questions where a user can 'select all' relevant answers to a question. Each answer will need to be queried separately when interrogating the data, and any responses that have been ticked will be marked as 'True'.

Each question that is set up is a single response and cannot be 'required'.

You may wish to use Bold / Normal text to contain the question, and then use subsequent check boxes to contain each answer option:



11.1.8	The main question for these check boxes is created using normal text:	
11.1.9	Response 1	<input type="checkbox"/>
11.1.10	Response 2	<input type="checkbox"/>
11.1.11	Response 3	<input type="checkbox"/>

## Comments

Clicking the  icon next to a question displays Registry team help text for that question. You can also use this button to add a comment next to a particular question for that patient. This might be an explanation for a seemingly unlikely value, or useful contextualising information that isn't recorded as part of the main dataset.

Although data within custom fields won't be analysed routinely, please be aware that the text can be accessed by the central Registry team, as well as anyone who has access to that patients' Registry record. The Registry team may use comments in order to resolve a data query when analysis is carried out.


## Print friendly

To print the tab you are currently looking at, click the  button above the data entry forms. To print all tabs at once select  before clicking the Print button. Selecting print will generate a print preview from which you can choose your printer and printing preferences before printing as normal.

Please be aware that, if your user permission level permits, patient identifiable data will be included in this print-out. Do not send printing to an unsupervised printer. All instances of printing patient data are included in the central audit log.

## Data definitions

### Help text

You can access help about individual fields by clicking the  icon next to individual fields. Please check this box before sending a query to the Registry team.

### Data dictionary

A data dictionary is available to download from the Registry portal as well as the Cystic Fibrosis Trust Registry web pages. This shows all of the variables collected in the Registry, their change history, as well as applicable validation and business rules.

### Importing data

If you have a hospital system that collects data relevant to the UK CF Registry, that is able to export to CSV, it is possible to import data into the system. Please contact [registry@cysticfibrosis.org.uk](mailto:registry@cysticfibrosis.org.uk) for more information on how to format your data correctly.

### Data entry deadlines

The deadline for entering data is the 31 January the following year. So, 2016 data must be complete by 31 January 2017. In order to ensure all data are accurate and complete by the deadline it is recommended that data are entered throughout the course of the year. As a minimum, data entry should be up to date every three months. This will also enable you to get the most out of the reporting functions in the Registry.

# Reporting and exporting

## Dashboard

The dashboard is designed to give an ‘at-a-glance’ view of your data completeness and key clinical outcomes. This tool will continue to be developed over time, so feedback to the Registry team is welcome.

The dashboard will default to showing aggregated data for all of the sites you have permission to view. If insufficient applicable data exists the chart will display blank.

On any chart, hover over data points to see a pop up with the precise values.

When hovering over different dashboard charts, you will see two different cursor types:



Click and drag to move your dashboard items around – you can move the ones you use most to the top, for example



This icon shows for charts where you can drill down to view the same chart for specific centres and/or years, or for individual patients over time.

When you’ve clicked on a chart, for example FEV<sub>1</sub>% predicted, you will be shown a larger version of the same chart. Use the drop down menus at the top to select a specific site and/or year. Leaving either of these drop down menus at their default will maintain the ‘all sites’ or ‘all years’ view. Click ‘go’ to refresh the chart according to your selection.

To view a chart for a specific patient, click through to the expanded view of a particular chart, and scroll down – you will see a patient list. Clicking on a patient will show that patient’s BMI and FEV over time. A ‘search’ box will be added shortly after launch to make it easier to go directly to specific patient dashboards.

## Chart overview

Charts will be added to and adapted over time. Charts included in the initial system roll out are:

Title	Purpose
Active patients	Shows how many patients are considered ‘active’ in your site(s). Criteria: Alive, data recorded in the previous two ‘locked’ years, and not ‘diagnosis reversed’ Drill down: None
Data completion (annual reviews)	Tells users how many annual reviews have been completed for active patients in the current data collection year. Acts as a marker of progression towards completion of the minimum required data. Drill down: Site and patient
Data completion (demographic)	Shows how many active patients have complete demographics records. In the new system all demographics will appear incomplete. A quick review of this section (takes around 1 minute) for each patient when you add their annual review will mark these records complete. Drill down: Site and patient

Title	Purpose
Data completion (pending microbiology)	The microbiology tab saves as 'complete' if a user indicates that microbiology samples have been sent, but results are pending. This chart shows sites which of their active patients have pending results which should be entered when available. Drill down: Site and patient
Data completion (unknown genotype)	The genotype tab saves as 'complete' if a user indicates that genotyping has been undertaken or the result is unknown. This chart shows sites which of their active patients have one or more 'unknown' genotype. It is our aim to have overall genotype completeness close to 100% for the CF population. Drill down: Site and patient
Median BMI	Shown for patients aged 20 and over. Drill down: Site and patient
Median FEV <sub>1</sub>	Shown for patients aged 5 and over. Drill down: Site and patient
Median weight percentile	Shown for patients aged 19 and under. Drill down: Site and patient
Patient profile Gender	Illustrates the mix of Male/Female patients for site(s) the user has permission to see. Drill down: None
Patient profile Genotypes	Illustrated the mix of genotypes for patients at the site(s) the user has permission to see. Drill down: Site

## Query builder

This tool helps you to interrogate the data that has been submitted by your centre(s) to the Registry. You can create groups of patients, and generate exports of those groups for further analysis locally. The query builder you will see on launch is version 1 – we intend to develop its usability further after go-live, and welcome your feedback. If you need help interrogating your data, please let us know.

Common queries are created and made available to all sites by the UK CF Registry team.

## Building a query

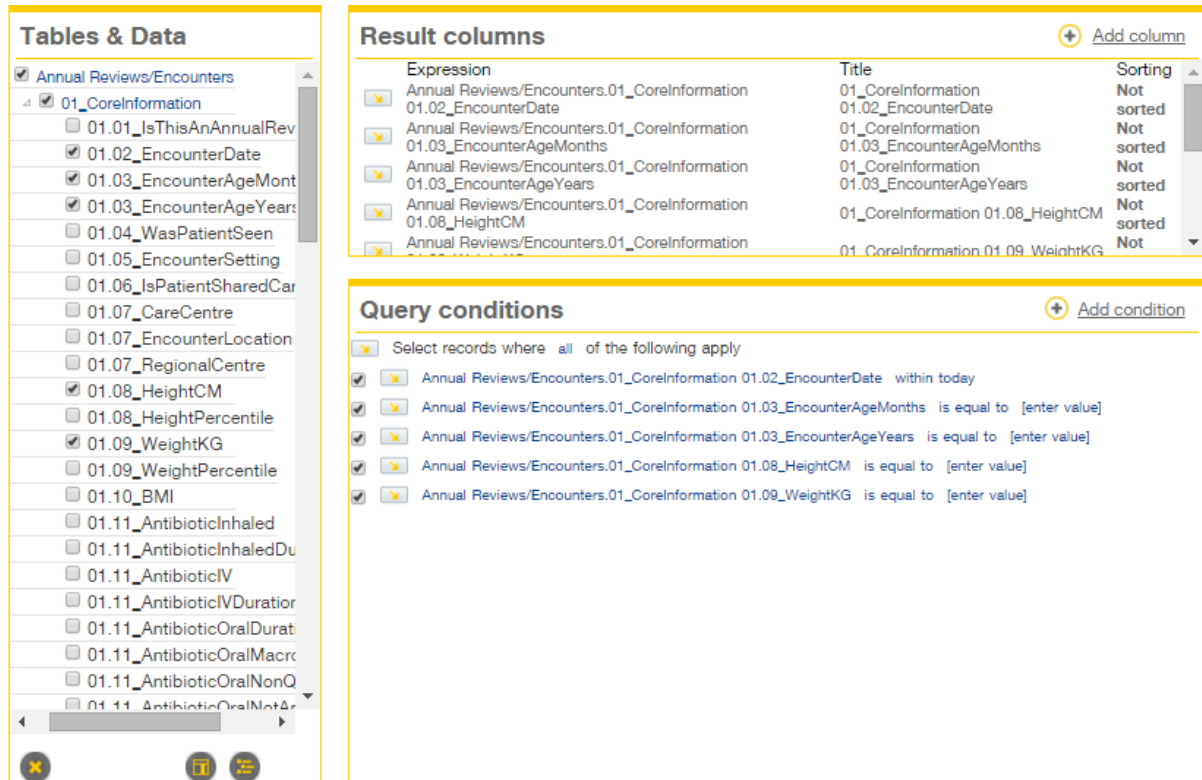
### Setting up a new query

- **Site:** Specify the CF site you would like to query, or select [All teams] to query all the sites you have access to.  
N.B. If you want to select a sub set of the sites you can access, select [All teams] then refine the query to include the ones you want using 'Sites' in 'Tables and Data', below
- **Query:** Use this drop down list to select a previously saved query, if relevant. If creating a new query make sure you click 'Save' when it's finished so that you can reuse it
- **Name:** If creating a new query, give it a descriptive name so you can refer back to it
- **Description:** Describe the query, so it's clear what it comprises of should you wish to reuse it or send it to other sites to use
- **Import/export:** This function allows you to easily share queries with other CF sites, or save queries locally before editing them.
  - **Import:** You can import a previously saved and exported XML file query using this function

- *Export:* You can export a query you have already created and save it locally as an XML file

*Adding query conditions*


Once you've set up the new query, you need to add conditions to the query, to define the group of patients you want to look at, and the results you want to generate based on that group.



*Tables and Data:* 'Tables' are groups that the variables are organised under. You can expand these to get to sub groups. Expanding 'Annual reviews/Encounters' will show the different tabs that the variables sit under. 'Data' are the variables collected in the Registry. The naming convention is TabNumber.QuestionNumber\_VariableName, for example '01.02\_EncounterDate' is the field that stores the date of the encounter, found in tab 1, question number 2.

*Result columns:* Add these using the button underneath the *Tables and Data* section. These are the columns that the query will return when submitted, and will be exported if you choose to. You may decide to have the same columns returned as from the query conditions, or you may wish to return a subset of columns, additional or different columns. You can specify how your results will be sorted using the 'sorting' column once your columns are added.

*Query conditions:* These are the building blocks of the query – and will determine what results are returned to you. Add variables to query using the button underneath the *Tables and Data* section. Add conditions to each variable by clicking onto the text after the variable. For example you can state that 01.02\_EncounterDate must be within 'this month', or between two dates that you can specify.

*Results:* When you're happy with the query you've created, scroll down to the 'Results' box and click  [Update Result](#). The first 50 results will show, as a sample. If you want to amend your query, do so, then refresh your results by clicking 'Update result' again.

If you want each patient to appear only once in your results, check the box that says 'distinct results only':



Distinct results means that a query looking for all patients who have an encounter after 01/01/2015 will return each patient with an encounter after this date only once. Leaving this box unchecked means the patient would appear multiple times, for each encounter they had after 01/01/2015.

When you're happy, you can export the results data to either Excel or CSV. by clicking the links. **If you want to reuse a query you've created, make sure you click 'Save' next to its name when you're finished.**

## Pre-set queries

Pre-set queries are designed to provide information commonly requested by CF sites, without each site having to create their own.

They are also designed to be building blocks, creating a cohort that you can edit or add to. To add to or amend either the results or query conditions for a pre-set query, first type a new name and then click 'copy', make your amendments and click 'save'.

**Please do not save existing pre-set queries, as this will over-write the basic queries used by all sites.**

### Active patients

This query shows all patients who are considered active, and should have an annual review encounter added before that data entry deadline that year. It includes patients seen in the previous two years, who have not been transferred out, had a diagnosis reversal, or died.

### Current medications

This query shows the pseudonymised identifier, encounter date, and all medications that are recorded between 1 January 2015 and 31 December 2016 as being 'still taken'.

## Exporting data

Use the 'export data' function when you want to download all data for a CF site within a given time period into Microsoft Excel. You might do this if you want to analyse your data, or run data queries outside of the system.

If you want to export a specific cohort of patients, such as all patients of a certain age or taking a medication, use the [query builder](#).

To export data go Patients > Patient export.

You will be presented with this screen:

## Export data

Site:

Data Sections:

Date from:  To:  (Date of birth range)

Data Type:  All Data  Anonymised  Pseudonymised

Locked/Unlocked Data:  Locked Data  Unlocked Data  Both (locked/unlocked)

[Download Report List](#)

**Site:** Allows you to select a site or, if you have access to more than one, all the sites you have permission to see.

**Data sections:** You can select demographics, annual reviews, or encounters. Note that in this system 'annual review' includes the PortCF Annual Survey and the Annual review encounter

If you wish to look at multiple sections together you can use the CFTID, or other identifiers (depending on the 'Data type' chosen) to link data to demographic records.

**Date from:** This defines the date range you wish to export data for. If exporting demographics, this is the patients' birth date, if encounters, this is the date of the encounter/annual review.

**Data type:** Defines the level of identifiability of the data you download. Only export the minimum data required. If you don't need identifiable data in order to carry out your analysis you should not export it. Data should be downloaded, saved, deleted, and/or electronically shredded in line with your institution's information governance policy.

- *All data:* This will export all relevant data stored on the system. If you have access to patient identifiable data, such as patient names, this will also be downloaded
- *Anonymised:* Data stripped of all identifiers will be downloaded. This means that the CFTID will not be included and you won't be able to re-identify patients after download, or search for them in the Registry system. Date of birth will be exported as MM/YYYY only. Age will be provided.
- *Pseudonymised:* Pseudonymised exports are the same as anonymised exports, but include the CFTID, which allows you to re-identify patients, and search for them in the Registry system.

**Locked/unlocked data:** If you only want to export data that has been locked (a process that happens each year after data entry closure) select 'locked data' if you only want data that are unlocked and can still be edited, select 'unlocked'. To download data regardless of the lock status, select 'Both'.

**Active/inactive:** This allows you to include or exclude inactive patients from your export. You may wish to export all of your active patients to ensure you've completed the mandatory data towards the end of the data collection year. Active patients are defined as patients who

have not been marked as deceased or transferred out of your CF centre, who have also had data entered in the prior two data collection years.