

Cystic Fibrosis Trust

UK CF Registry User Guide

Version 2.2
May 2026

Version history

Version number	Date	Details
2.0	November 2022	
2.1	28 July 2023	Updated section: 'Contacting the Registry team'
2.2	05 May 2026	Updated section: 'Data Entry Deadlines' Updated section: 'Transferring a Patient'

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Introduction

Welcome to the UK CF Registry. Please read this user guide before entering data onto the system.

Using the Registry

This user guide contains lots of useful information that will help you to use the Registry.

When entering data into a patient's record, you can hover over or click on the question mark symbol next to each question to display additional information.



Contacting the Registry team

You can contact the Registry team by emailing registry@cysticfibrosis.org.uk. Feel free to contact us about any queries or feedback you may have.

Please do not send identifiable patient details, including NHS numbers, by email.

You should only ever reference specific patients by using their Registry ID.

If you do not have the patient's Registry ID, you can use their initials and date of birth. You must use [SECURE] (in capitals, including the square brackets) as the subject line when sending identifiable information such as dates of birth. This is for data security purposes and will ensure that the email is encrypted.

Data entry deadlines

The deadline for entering data for each year is 31 January the following year. For example, all 2026 data must be entered by 31 January 2027. After this deadline, existing encounters and annual reviews will be locked and will not be able to be edited.

It is **strongly recommended** that you enter data throughout the year as this will ensure completeness and enable you to get the most out of the Registry's querying and reporting functions.

As a minimum, data entry should be up to date every three months.

Your account

Logging in

The UK CF Registry can be found at <https://cfregistry.org.uk>. Click on the 'Login' tab at the top to log in to the Registry.



Each time you log in, you will be asked to confirm your agreement with the Registry terms of use. Please read these carefully before proceeding.

Setting or resetting your password

Login

Please enter your login details...

Username:

Password:

Login

If you know your Username (usually your email address), but need to set your password or forgotten your password?

Forgotten Password

If you are experiencing problems logging in, please contact UK CF Registry Team.
Email: registry@cysticfibrosis.org.uk
Telephone: 020 3795 2180

In order to set your password for the first time, you will first need to be set up as a user by your Site Administrator. Your username should be your NHS or academic institution email address.

To set your password, click on the 'Forgotten Password' button and enter your email address. You will be sent an email containing a link that will allow you to enter a new password of your choice.

Reset Password



Password Reset <noreply@cfregistry.org.uk>
To LUCY PETRYCKI

Please reset your password by clicking the following link: [Reset Password](#)

You can also use this process to reset your password if you forget it.

Two-factor authentication

The Registry uses two-factor authentication to verify your identity and protect patient data. When you log in for the first time from a new web browser, a verification code will be sent to the email address that you use for your username.

Security Code



CFTR NoReply <noreply@cfregistry.org.uk>
To LUCY PETRYCKI

UK CF Registry - Test

Your security code is

If you have any queries or questions, please contact us on the details below:

UK CF Registry Team
Tel: 020 3795 2180

Email: registry@cysticfibrosis.org.uk

If you haven't received a code after 5 minutes, check your junk and spam folders, and contact the Registry team if it hasn't arrived.

Once you've received the code, enter it in the box on the login screen. You can tick the 'Remember browser' box to avoid having to repeat this process next time you log in.

Two-Factor Authentication

Enter verification code

Please enter the authentication code that has been sent to you using the method you selected.

If you have not received an email with your security code within 5 minutes, please check you junk/spam folders as sometimes they may get directed there.

Code:

Remember browser

Shared computers

For security purposes, two-factor authentication is re-enabled whenever a new user logs into the Registry using the same browser on the same PC. As a result, users who share a computer may have to repeat the verification process when they log in.

Homepage

The Registry homepage is the first screen you will see when you log in to the Registry. It includes important information about deadlines and recent software updates. It also has a number of links to useful resources such as other user guides, Registry consent forms, and patient information sheets for patients of different ages.

Updating your profile

By clicking on the 'My profile' tab at the top, you can update your name and email address by changing the text in the boxes and clicking on the 'Update settings' button. You can also change your password and see which cystic fibrosis user sites you have permission to access.

Please note that changing your email address on this screen will **not** change the username you use to log in to the Registry.

Home Patients ▼ Studies ▼ Resources ▼ Dashboard ▼ Dashboard HC ▼ Reports ▼ Admin Reports ▼ Staffing Tool ▼

My profile User management ▼ Data Query ▼ Stats ▼ Administration ▼

User details

User name	lucy.petrycki@cysticfibrosis.org.uk
Full name (including title)	<input type="text" value="Lucy Petrycki"/>
Email	<input type="text" value="lucy.petrycki@cysticfibrosis.org.uk"/>

User sites

No records to display

Users

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 who 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, which confirm which users still require access to their site. 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.

Site Users

Site Users (previously called Site Editors) are able to:

- edit unlocked data
- add new encounters
- add new annual reviews
- add new patients
- view reports
- query data
- export data

Site Readers

Site Readers are able to:

- view all data for their site
- view reports
- query data
- export data

Site Readers cannot edit data within the Registry system.

Setting up, editing, and disabling users

Site Administrators are able to set up new users and edit or disable existing users.

Setting up new users

Before setting up a new user, it is important to establish the level of access required. You should always give a new user the minimum required level of access, referencing the user roles detailed above.

You can only assign user permissions that are equal to or lower than your own, so some options (such as CFT Administrator) will be disabled.

To set up a new user:

1. Go to the user management screen and click on the 'Add new' button.

Users

Site:

Locked: Search:

2. Enter the user's full name and email address. This must be a valid NHS or academic institution email address. Do not use other less secure email providers.

3. In the list of permissions, tick the box next to 'CF sites' to tell the system that you are setting up a new site user.

4. In the 'Role' box, you will see a list of the sites that you have access to. Use the drop down menus to select whether the new user should be a Site Administrator, Site User, or Site Reader. You can select different permission levels for different sites.

5. Click on the 'Insert' button to save your changes and finish registering the new user. They can now set their password by following the instructions in the 'Logging in' section of this guide.

Editing users

To edit a user's details or permission levels, go into the user management screen and find the user by typing their name into the search box. Click on the pencil icon at the end of the row.



This allows you to edit the details that were entered when the user was set up. Please note that you **cannot** change the user's username, even if you update their email address.

Once you've finished updating the user's details, click on the 'Update' button to save your changes.

Disabling users

If a user no longer requires access to the Registry, you must disable their user account. To do this, type their name into the search box and click on the pencil icon at the end of the row. Tick the box next to 'Locked', then click on the 'Update' button at the bottom of the user's record.

Locked

Audit Log

Site Administrators can use the Audit Log to access an overview of actions relating to data at their site.

The Audit Log contains a large volume of information, so it is recommended that you filter your results. For example, if you want to find actions by a specific user, enter their name in the 'User name' box.

You can use the tick boxes at the top to filter results by event type.

Event type: Data change Errors Information Warnings

Managing patients

Record management

The record management screen is the patient data home screen. To access it, hover over the 'Patients' tab at the top, then click on 'Patient data' in the drop-down menu.

From the record management screen, you can:

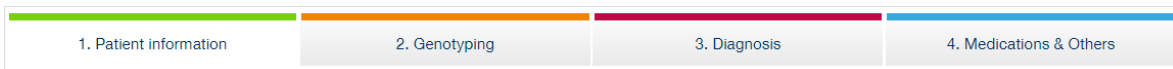
- view the completeness of individual patients' data
- search for patients
- add new patients
- enter data

Colour coding

Completeness of data within patient records is represented using the following colour scheme:



For example:



In this patient's record, the 'Patient information' tab is fully complete. The 'Genotyping' tab is partially complete, but has some information missing. The 'Diagnosis' tab has at least one error within the data (in this case, the date of diagnosis that had been entered was before the patient's date of birth). The 'Medications & Others' tab has not been opened yet and therefore does not contain any saved data.

Searching for a patient

You can search for a patient using the search box on the record management page. You can search for patients using their:

- Registry ID
- date of birth (in the format DD/MM/YYYY, including the slashes)
- NHS number (in the format 000-000-0000)
- full name
- first name or surname

Advanced search

You can use the advanced search function by clicking on the 'Advanced' button to the right of the search box.

Search... Include Inactive Patients: Study patients: All

This allows you to search for a patient or a group of patients in more detail.

Include Inactive Patients: Study patients: All

Created by:

Case id:

Last name:

Birth name:

First name:

Middle name:

DoB from: DoB to:

NHS number:

CHI Number:

DoD from: DoD to:

Adding a new patient

Before adding a new patient to the Registry, **always** use the search function to ensure that they do not already have a record at your site. We also ask that you contact the Registry team to confirm that the patient is not already on the Registry under another site.

To add a new patient:

1. Select the name of the CF centre where the patient receives care. If they receive care at a clinic, you should select the clinic, not the CF centre.
2. Click on 'Add record' and confirm that the patient has signed a consent form giving consent for their details to be added to the Registry. If possible, please upload a copy of the consent form to the patient's record.
3. As you enter the patient's demographic information, the system will alert you if the details appear to match another record, suggesting that the patient is a duplicate. Before overriding this alert, check whether this patient already has a record at your site, or whether they are listed under another site and have not yet been transferred.

4. Don't forget to click on the 'Save' button to save your data.

Transferring a patient

If a patient permanently transfers to your site from elsewhere, you should contact the Registry team and ask for their record to be transferred across to their new site ensuring you have obtained informed consent before requesting.

You do not need to contact the Registry team if a patient transfers away from your site.

Duplicates

The system can prevent duplicate records from being created by validating unique patient information (such as their NHS number or CHI number) against all other records held on the Registry. If a duplicate record is identified, an email alert will be automatically sent to the Registry team. The Registry team will contact you to inform you that the record is a duplicate and that the new record will be deleted, along with any data that has been entered. The Registry team will then transfer the patient's existing record across to your site. Any data already entered will need to be re-entered.

In the unlikely event that you notice that a duplicate record has been created, please contact the Registry team and provide the Registry ID of both patient records.

Entering data

Data entry features

Error messages

When you click on the 'Save' button to save your data, a colour coded bar will appear at the bottom of the screen. A green bar indicates that your data is complete and has been saved without any issues.

PAGE SAVED - COMPLETE

An orange bar indicates that some data is missing and/or there are errors within the data.

PAGE SAVED - ERRORS OR INCOMPLETE FIELDS FOUND [show errors](#)

Clicking on 'show errors' will show a list of links to the questions that have errors or incomplete fields, allowing you to locate them quickly by clicking on them. Each question with errors or incomplete fields will be highlighted with an explanation of why that question has been flagged up.

DIAGNOSIS

3.1. Date of Diagnosis

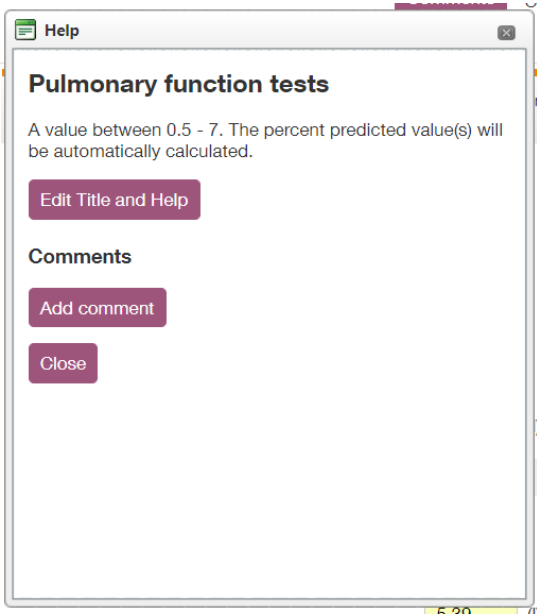
a. Date diagnosis of CF was confirmed with the patient or parent	01/01/2000
	Cannot be before date of birth
b. Indicate if diagnosis date is accurate or estimated	<input type="radio"/> Estimated <input type="radio"/> Exact
	Required

Adding comments

Hovering over or clicking on the question mark symbol next to each question will display help text for that question.

You can also click on the question mark to add a comment to a question. For example, you may wish to add an explanation for a seemingly unlikely value or provide contextualising information that isn't recorded as part of the main dataset.

Please be aware that any comments added to a patient's record can be viewed by anyone who has access to that record, including the Registry team. The Registry team may view comments in order to resolve data queries when data cleaning is carried out.



Demographics

Each individual patient’s demographic data is always associated with their record, even if their care moves from one site to another. It isn’t locked as part of the annual reporting cycle and it 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 the annual report and calculations of funding available to sites.

Demographic data should be checked for each patient at least once per year even if it is marked as complete. This is to ensure that all of the patient’s details, such as their surname and postcode, are up to date.

To view or edit a patient’s demographic data, click on the pencil icon at the end of the row in the record management screen.



Consent

You will be asked to confirm that the patient has given written consent whenever you create a new patient record or accept a patient transfer from another CF site.

If a patient withdraws consent, you should change their consent status to ‘Consent withdrawn’ in the demographics tab. Their record will be locked and all of the data associated with that patient will become read-only. You should then contact the Registry team to discuss removal of the patient’s data from the Registry.

Genotyping

Each patient on the Registry should have genotyping data for at least two mutations in their record. You can still save a page with less than two mutations, but the record will show up as 'incomplete' on the record management screen.

To enter genotyping data, click on the 'Select...' box and start typing the genotype/mutation. The list will automatically skip to the correct listing for that genotype. You should only enter genotyping data as 'Other' if you are completely certain that the genotype is not included in the list. In these cases, you must transcribe the genotype exactly how it appears on the lab report. Entering genotypes as free text makes them much more difficult to categorise and analyse.

If you select a genotype that is associated with Poly-T tracts, an additional question will appear. If Poly-T status is not included on the patient's lab report, or if it is included but is shown as 'unknown', you should tick the box next to 'Not known/Not applicable'.

2.2. How many mutations have been identified?

2.3. Genetic mutation 1 (*Legacy/Protein/cDNA*)
Search by typing in the dropdown box

Mutation 1 Poly-T tract

5T 7T 9T Not known/Not applicable

2.4. Genetic mutation 2 (*Legacy/Protein/cDNA*)
Search by typing in the dropdown box

Diagnosis

The 'Diagnosis' tab collects information about when and how a patient was diagnosed with cystic fibrosis. It also collects outcome data about death and diagnosis reversal.

Medications and others

The 'Medications & Others' tab collects information about:

- chronic medications (including historical chronic medications)
- quality of life (CFQ-R scores)
- vaccinations
- COVID-19
- liver enzymes

Encounters and annual reviews

To add a new encounter or annual review, click on the folder icon to the left of the patient's CFTID, then click on the plus icon next to 'Add new Annual Review or Encounter'.



Encounters

An encounter is any event where a patient is assessed by their CF care team. Encounters may be inpatient, outpatient, or virtual. You can also record an encounter whenever a scheduled visit does not take place, such as if a patient does not attend or if their care has been transferred to a new site.

Every patient should have at least three encounters recorded each year. These encounters should, at a minimum, include the patient's height, weight, and FEV₁ measurements.

Annual reviews

The annual review includes all data since the previous annual review, and therefore includes more detailed data than a standard encounter. The information from each annual review is used for tariff payments, centre grant payments, and the annual report.

Every patient should have one annual review recorded each year. This should be carried out at a time when the patient is not experiencing an exacerbation.

If a patient has not had an annual review in the past year, a 'virtual' review must be compiled from the patient's notes at a time within the past year when they were stable.

Core information

1. Core Information	2. Admissions & IVs	3. Investigations	4. Chronic Medications	5. Culture & Microbiology	6. Complications	7. Growth & Nutrition	8. Physiotherapy	9. Lifestyle	10. Outcome	11. Custom fields
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The 'Core information' tab is the first tab you are brought to when you begin to enter an encounter or annual review. It primarily collects information about the encounter itself, as well as some information about the patient.

If a patient is shared care or is being seen at a site that is not their usual place of care, you can indicate this here and enter the relevant information.

1.6. Is this patient shared care? Yes No

1.7. Locations

a. Encounter Location

b. Where does this patient receive care?

c. Which is the patients' regional centre?

Admissions and IVs

If there are no admissions or IVs to report, simply select 'None' in the three drop down menus.

Investigations

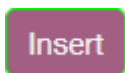
Entering FEV₁ data in encounters throughout the year will ensure that the 'Best FEV₁' field is automatically populated when you record an annual review. Please check whether the patient has had a higher FEV₁ recorded and amend the field if needed.

As of November 2018, all FEV₁ % predicted values are calculated using GLI methodology. Historical Knudson values are still accessible via the Query Builder.

Chronic medications

Chronic medications are any medications (including vitamins) that a patient has been prescribed for three months or more. The chronic medications tab collects details of these, along with drug intolerances, CFQ-R questionnaire scores, and COVID-19 vaccination status.

To add a new medication to a patient's record, click on 'Add new Chronic Medications/Drugs details' at the top of the medications table. Don't forget to click on 'Insert' after entering the data.



A patient's list of chronic medications will be carried through to new encounters and annual reviews provided that their encounters have been entered chronologically and there has not been a gap of 18 months or more between encounters. This means that medications do not need to be entered every time you record information about a patient. You should review each patient's medication list regularly and edit it as necessary.

If a patient has stopped taking a medication, do not simply delete the medication from the list. Instead, you should click on 'edit' and record when and why the patient stopped taking it.

I. Are they still taking the drug? Yes No

i. End date

ii. Reason stopped

- No benefit
- Non-compliant
- Intolerable Cough
- Bronchospasm
- Haemoptysis
- Nausea
- Vomiting
- Abnormal liver function tests
- Dysgeusia
- Tendon Rupture
- Tendonitis
- Other Tendinopathy
- Liver Disease
- Treatment complete
- Other (Please specify)

Culture and microbiology

Entering culture and microbiology data in encounters throughout the year will ensure that some fields in this tab are automatically populated when you enter an annual review.

Complications

The 'Complications' tab collects information about short-term and long-term complications. Long-term complications will be carried over to the patient's next annual review.

Growth and nutrition

The 'Growth & Nutrition' tab collects information about nutritional intake and any supplemental feeding a patient may receive.

Physiotherapy

The physiotherapy tab collects information about:

- airway clearance
- non-invasive ventilation
- exercise tests
- continence
- postural abnormalities

Clicking on 'Add new Exercise' in the exercise section will allow you to record details of specific exercise tests.

The screenshot shows a web form titled '+ Add new Exercise'. Inside the form, there is a sub-header 'Add new' with a close button. Below this, the form is titled 'Exercise'. It contains two numbered sections: '1. Exercise test' and '2. Test date'. The '1. Exercise test' section has a red background and lists five radio button options: Shuttle test, 6 minute walk test, Step test, CPET, and Other. Below these options is the word 'Compulsory' and a yellow input field with the placeholder 'DD/MM/YYYY'. The '2. Test date' section also has a red background and a yellow input field with the placeholder 'DD/MM/YYYY', with 'Date compulsory' written below it. At the bottom of the form are two buttons: 'Insert' and 'Close'.

Lifestyle

The 'Lifestyle' tab collects information about:

- smoking
- education and employment
- marital status
- pregnancy and birth

Some of these questions will only appear in a patient's record when they are over a certain age.

This tab only needs to be filled out when you are recording an annual review.

Outcome

The 'Outcome' tab is used to indicate whether a patient has died or had their diagnosis reversed.

If you indicate that a patient has died or had their diagnosis reversed when recording an annual review, their record will automatically be updated and set as inactive.

This tab only needs to be filled out when you are recording an annual review.

Custom fields

The 'Custom fields' tab is used to create fields for users to enter additional data that is collected by your site. These can be only be set up by Site Administrators.

To access a more detailed guide about the different types of custom fields, please contact the Registry team.

Printing

You can print a copy of the tab you are viewing by clicking on 'Print' at the top of the record. To print a copy of all of the tabs in that section of a patient's record, click on 'View All Tabs' before you click on 'Print'. Clicking on 'Print' will generate a print preview screen where you can preview the pages and select your printer before you print.

[View All Tabs](#) [Print](#)

Please be conscious of the fact that patient identifiable data will be visible on the printout. Do not send printing to an unsupervised printer. Details of all patient data printouts are recorded in the Audit Log.

Reporting and exporting data

Please note that the data and graphs shown in this section are examples from the Registry test site and do not represent actual patient data.

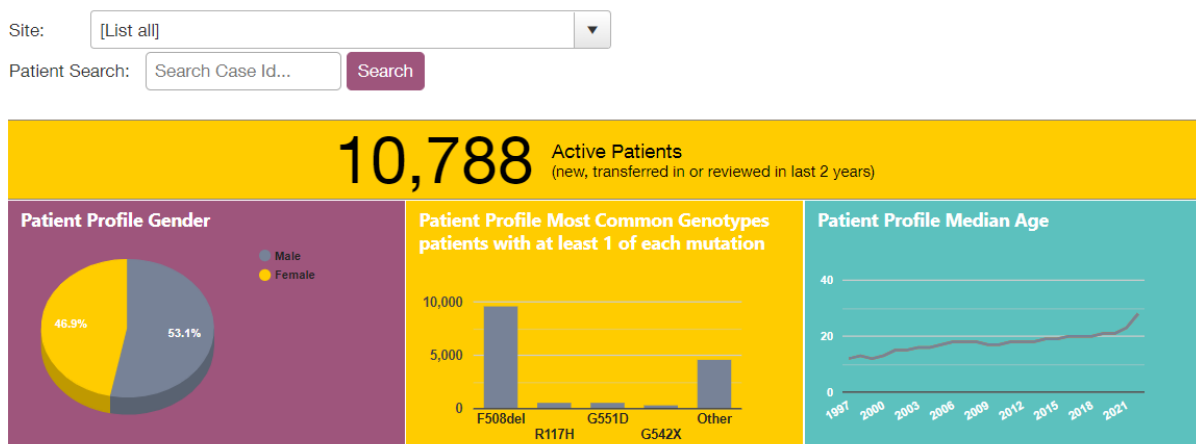
Dashboard

The dashboard gives you an at-a-glance view of the data completeness and key clinical outcomes of the sites you have access to. You can access it by hovering over the 'Dashboard' tab at the top and clicking on 'Dashboard Homepage'.

There are three different dashboards available to view. The Patient Profile dashboard below is the default one that you will see when you click on 'Dashboard Homepage'. You can also view the Data Completion dashboard and the Health Indicators dashboard by clicking on the links.

Only CFT Administrators can see data for all UK sites. Users can view data for all of the sites they have access to or use the drop-down menu to focus on one particular site.

UK CF Registry Patient Profile Dashboard



[View Data Completion Dashboard](#)

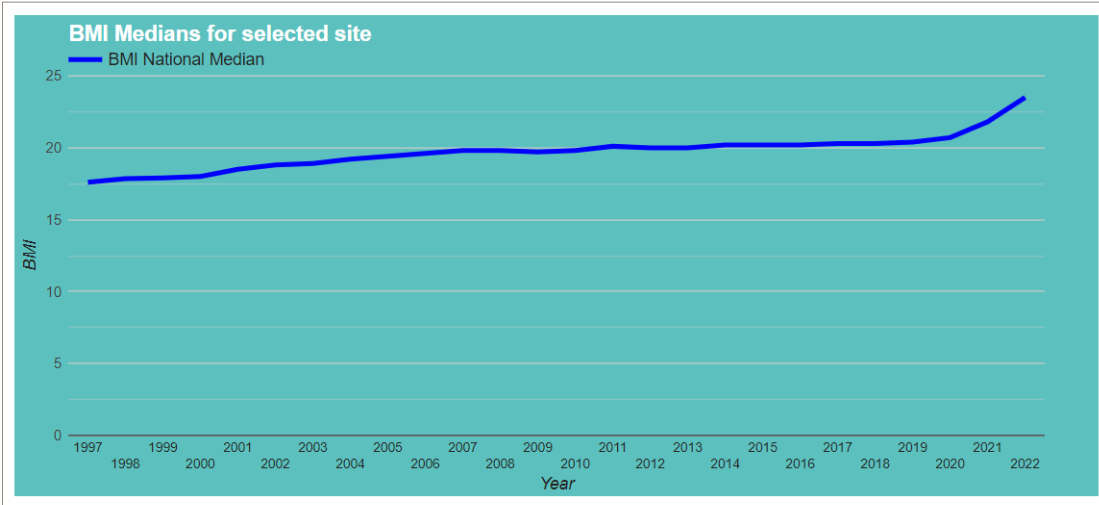
[View Health Indicators Dashboard](#)

You can rearrange the different panels by clicking and dragging them. You can also hover over the graphs to see more information. For example, hovering over the bars on the genotype bar chart will show how many patients are in each group.

Clicking on a graph will bring up a larger version that you can use to find more information. For example, clicking on the BMI graph on the Health Indicators dashboard leads to this screen.

BMI Details

Site: Year:



[Printable version](#)

Using the boxes at the top, you can select a site and a year and click on 'Go' to narrow down the data that is included in the graph. This will also bring up a list of the relevant patients and their details below the graph. You can click on a patient's Registry ID to view a graph of that patient's individual data.



[Printable version](#)

Case ID Number	Median BMI	Review Year
	14.20	2019
	15.30	2019
	15.70	2019
	15.90	2019
	16.20	2019
	16.20	2019
	16.30	2019
	16.40	2019
	16.80	2019
	17.10	2019

Exporting data

You can use the data export function to download a site's data from a given time period and export it into Microsoft Excel. This may be useful if you wish to analyse your data or run data queries outside of the Registry system.

Data exports must be password protected in order to comply with GDPR regulations. This means that the file you download will be zipped and you will need to use unzipping software to open the file. Please see the 'Using 7-Zip' section below for more details.

If you wish to export data about a particular set of patients, such as patients who are a certain age or taking a certain medication, you should use the Query Builder instead.

To export data, hover over the 'Patients' tab and click on 'Patient Data Export'.

Core Export data

Site:

Data Sections:

Date from: To: (Date of birth range)

Data Type: All Data Pseudonymised Anonymised

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

Downloads will be in CSV format stored within and encrypted, password protected zip file. The password that you enter below will be required to open the zip file. In order to open the zip file you will need zip file software like 7-zip (<https://www.7-zip.org/>).

Download password:

Site: Use the drop down menu to select the relevant site. You will only be able to select sites that you have access to.

Data sections: Use the drop down menu to select which data section you wish to export. You can only export one section at a time. If you wish to look at multiple sections, you can use the CFTID or other identifying details to cross reference and link data together.

Dates: You can choose which time period you would like to export data from. If you have selected demographics as the data type, this will be the patients' date of birth. If you have selected annual reviews or encounters, it will be the date of the encounter.

Data type: Select the level of identifiability of the data you want to download. You should only export the minimum data required and should not download identifiable data unless you require it for your analysis. 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 of the relevant data and will include identifiable details such as names if you have access to these.

Anonymised: The data you download will not include any identifiers such as the CFTID. You will not be able to re-identify patients or search for them on the Registry system after exporting. Patients' date of birth will be exported as MM/YYYY only.

Pseudonymised: Exporting pseudonymised data is the same as exporting anonymised data, but the CFTID will be included. You will be able to re-identify patients and search for them on the Registry system.

Locked/unlocked data: Data is locked every year after data entry closes.

Locked: This option will only export data that was entered prior to the most recent data entry closure.

Unlocked: This option will only export data that is unlocked and can still be edited.

Both: This option will export all data regardless of whether it is locked or not.

Password: Enter a password of your choice (it doesn't have to be the same as your Registry password). You will need to enter this password when you open the CSV file containing your results.

Query Builder

A separate guide on how to use the Query Builder can be accessed by hovering over the 'Data Query' tab and clicking on 'Query Builder User Guide'.

Using 7-Zip

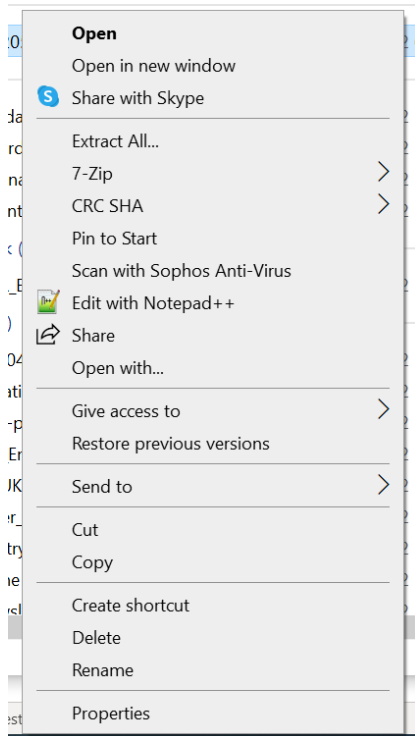
Because of the requirement to password protect data export files, you will need to have unzipping software such as 7-Zip installed on your computer.

The screenshot shows a web interface for exporting data. At the top, there is a 'Results ?' header and a 'Distinct Results Only' checkbox. Below this is an 'Export to Csv' button. A text box explains that downloads will be in CSV format, stored in an encrypted, password-protected zip file, and that a password will be required to open it. It also mentions that zip file software like 7-zip is needed. Below the text is a 'Download password:' label and a text input field containing a masked password '.....'. To the right of the input field is an 'Update Result' button.

When you click on 'Export to Csv', a box may appear at the top right corner of your browser with options to open or save the file. You do not need to click on anything and can just ignore it.

To open the export file:

1. Click on the folder icon on your taskbar to open the File Explorer.
2. Click on 'Downloads' in the menu on the left.
3. The results you just downloaded should be at the top of the Downloads folder. Right click on the file, then hover over '7-Zip' and click on 'Open archive' at the top of the list.



4. A new window should open containing a readme file and your Excel results. Double click on the Excel file and type in the password.



If you are having trouble opening a file you have downloaded, please get in touch with the Registry team and we will try to help.