



UK FSHD Patient Registry Registration User Guide

How to join the UK FSHD Patient Registry as a patient, or as the parent/carer of a patient

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Step 1 – Setup your user account

- Go to the registry website - <https://www.fshd-registry.org.uk/>
- Click 'Register now'
- You will see the registration page that looks like the image below. Add your information, tick the box at the bottom of the page, then click the green 'continue' button.
- Please ensure you keep your email address and password somewhere safe – you will need to remember the details you have used in order to log in to the registry to provide updates in future.



INFORMATION FOR PARTICIPANTS

INFORMATION FOR PROFESSIONALS

INFORMATION FOR RESEARCHERS

CONTACT US

USEFUL ORGANISATIONS

LEAFLETS, NEWSLETTERS AND POSTERS

POTENTIAL THERAPIES

GLOSSARY

PUBLICATIONS

PROJECTS SUPPORTED

REGISTER NOW

LOGIN

Register now

Please complete this form and click on the "Continue" button to start the registration. Please see the patient information and data protection pages for information on how the data you enter will be used.

If you have already registered and would like to update your data or add another patient, you don't have to fill in this form again. Just go to the login page and login with the e-mail address and password you previously registered with.

Note to professionals: Doctors and medical professionals cannot register here, if you are interested in being involved please contact us.

Personal data

Please enter your own details here, even if you are not the patient yourself. If you are registering a child as a patient, you will be able to enter his or her details in a later step. Please note that you must be the patient's parent or guardian to enter a patient other than yourself.

First name(s) Surname

Date of birth *as day/month/year, e.g. 19/03/1967*

Sex
 male
 female

User account

With your e-mail address and the password you choose here, you can log in at any time to view or edit your data. In order to protect your personal data against unauthorised access, please choose a password which is hard to guess and write it down in a safe place. Note that the password is case-sensitive. Your password must be at least 6 characters long.

E-mail address *e.g. joe_bloggs@example.com*

Password

Repeat password

I consent to the storage of the information above as well as my contact data as described in the [Data Protection Statement](#) and agree to be contacted about my registration if needed.

Continue
Cancel

Step 2 – Confirm your details

- Check that you have entered your name, date of birth, sex and email address correctly.
- Press the yellow 'back' button if you need to make any changes (don't use your web browser's back button).
- If you are happy your information is correct, press the green 'continue' button

- After pressing 'continue', your user account will be setup and you will receive a confirmation email, but **your registration is not yet complete.**
- You are, however, now able to complete the rest of your registration in stages if you wish, as you can log in and out of the website using your email address and password from step 1
- The following message will now appear in the top right of the screen when you are logged in:

Step 3 – Add your address

- Add your postal address on this page. Please ensure you select 'United Kingdom' from the country dropdown options.
- If you do not live in the UK, please [contact the registry curator](#) before continuing.

The screenshot shows a web interface for adding an address. On the left is a vertical navigation menu with the following items: INFORMATION FOR PARTICIPANTS, INFORMATION FOR PROFESSIONALS, INFORMATION FOR RESEARCHERS, CONTACT US, USEFUL ORGANISATIONS, LEAFLETS, NEWSLETTERS AND POSTERS, POTENTIAL THERAPIES, GLOSSARY, PUBLICATIONS, PROJECTS SUPPORTED, OVERVIEW, ADD PATIENT, and CONTACT DATA. Under CONTACT DATA, 'Account' and 'Address' are visible. The main content area features a green success message box with a checkmark icon: "Your changes have been saved. We have sent you an e-mail with the confirmation of your registration." Below this is the "Address" section, which includes the instruction "Please enter an address through which we can contact you." and the label "Address Street with house number and any extra address lines". The form contains three input fields for the address, with the first containing "1 fake street". Below these are fields for "Postcode" (containing "TEST"), "Town" (containing "Faketown"), and "State/County" (with the label "Optional"). A "Country" dropdown menu is set to "United Kingdom". At the bottom of the form are "Save" and "Cancel" buttons.

Step 4 – Add your phone number

- Add your phone number(s) on this page
- Please note we will only contact you by telephone if we are unable to reach you by email. It is important to have more than one way of contacting you in case you lose access to the email account you used to register.

The screenshot shows the UK FSHD Patient Registry interface. At the top left is the logo. At the top right, a notification bar says "You are logged in as user test@fakeemail.com." with a "LOGOUT" link. A left-hand navigation menu lists various sections: INFORMATION FOR PARTICIPANTS, INFORMATION FOR PROFESSIONALS, INFORMATION FOR RESEARCHERS, CONTACT US, USEFUL ORGANISATIONS, LEAFLETS, NEWSLETTERS AND POSTERS, POTENTIAL THERAPIES, GLOSSARY, PUBLICATIONS, PROJECTS SUPPORTED, OVERVIEW, ADD PATIENT, and CONTACT DATA. The main content area is titled "Phone numbers" and includes a green success message: "Your changes have been saved." Below this, it asks the user to enter at least one phone number, including the country code (e.g. +44 for the UK). There are two input fields: "Home phone number" with an example "e.g. +44 191 1234 5678" and "Mobile phone number" with an example "e.g. +44 7812 345 678". Both fields contain the number "123". At the bottom of the form are "Save" and "Cancel" buttons.

Step 5 – Add patient information

- On this page you should declare whether you are registering for yourself, or for someone else.
- You can come back to this page if you need to add another patient - you can only register one patient at a time.
- Please add the patient's NHS or PPS number if known, then press the green 'continue' button to proceed.

UK FSHD
Patient Registry

You are logged in as user test@fakeemail.com. [LOGOUT](#)

INFORMATION FOR PARTICIPANTS

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PROJECTS SUPPORTED

OVERVIEW

ADD PATIENT

CONTACT DATA

Your changes have been saved.

Add patient

Please enter the following data regarding the patient.

Please enter the following data regarding the patient. If you are the patient yourself, the name, date of birth and sex you have already entered will be used. If you are the parent or guardian of the patient you will be asked to enter their details in the next step.

Relation to the patient

I am the patient myself.

I am the parent or guardian of the patient.

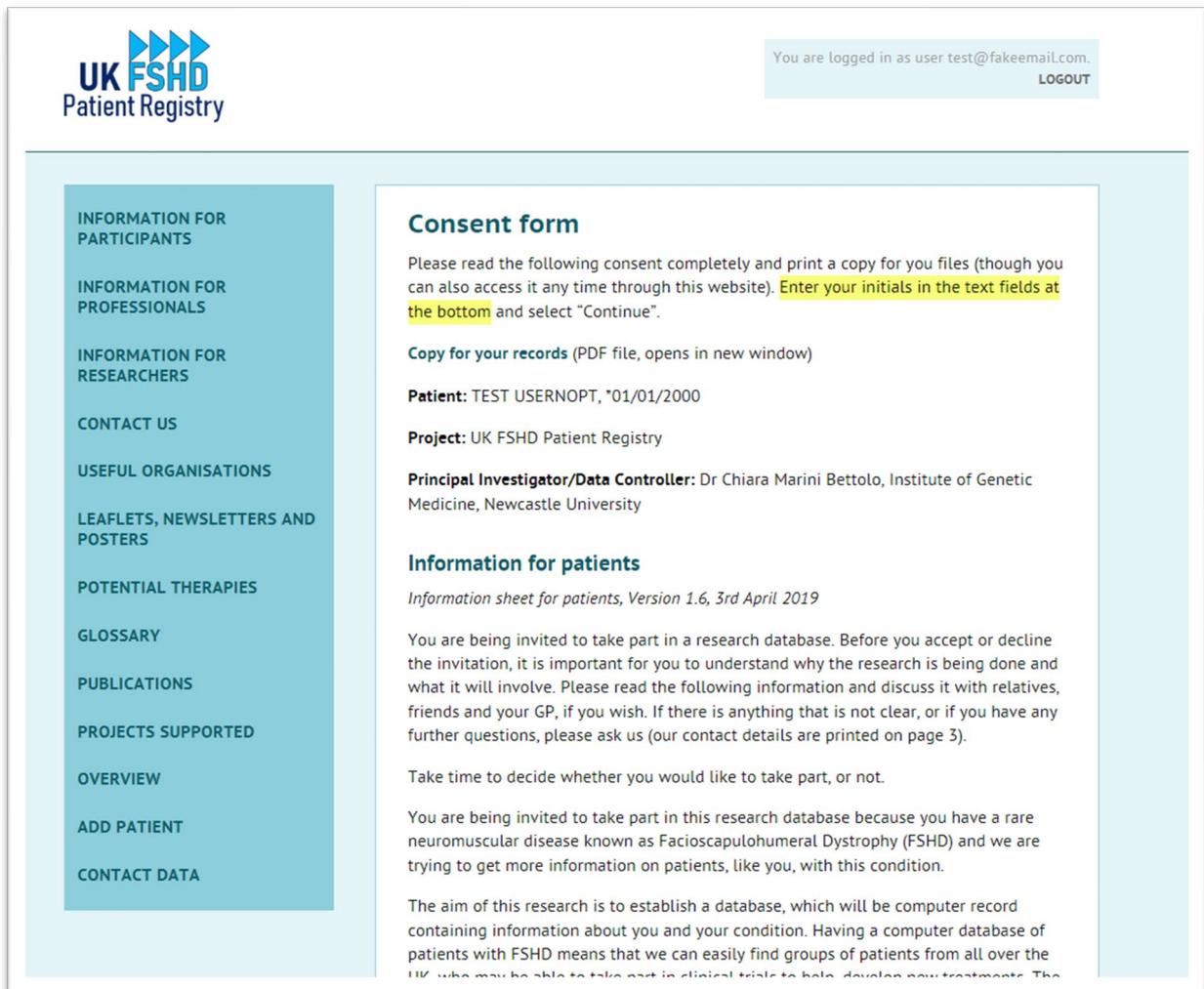
NHS number of patient (UK residents)

PPS number of patient (Irish residents)

[Continue](#) [Cancel](#)

Step 6 – Complete the patient consent form

- Please read through the consent form on this page. If you are registering on behalf of a patient, please ensure they understand all the information provided
- If you or the patient have any questions about anything in the consent form, please [contact the registry curator](#) before continuing.
- If you do decide to pause your registration at this page, please be reassured that you can pick up the process from this point and won't need to start from the beginning.



The screenshot shows the UK FSHD Patient Registry website interface. At the top left is the logo for the John Watton Muscular Dystrophy Research Centre. At the top right, it says "You are logged in as user test@fakeemail.com." with a "LOGOUT" button. The main content area is divided into a left sidebar and a main content area. The sidebar contains a list of navigation links: INFORMATION FOR PARTICIPANTS, INFORMATION FOR PROFESSIONALS, INFORMATION FOR RESEARCHERS, CONTACT US, USEFUL ORGANISATIONS, LEAFLETS, NEWSLETTERS AND POSTERS, POTENTIAL THERAPIES, GLOSSARY, PUBLICATIONS, PROJECTS SUPPORTED, OVERVIEW, ADD PATIENT, and CONTACT DATA. The main content area is titled "Consent form" and contains the following text:

Please read the following consent completely and print a copy for you files (though you can also access it any time through this website). **Enter your initials in the text fields at the bottom** and select "Continue".

Copy for your records (PDF file, opens in new window)

Patient: TEST USERNOPT, *01/01/2000

Project: UK FSHD Patient Registry

Principal Investigator/Data Controller: Dr Chiara Marini Bettolo, Institute of Genetic Medicine, Newcastle University

Information for patients

Information sheet for patients, Version 1.6, 3rd April 2019

You are being invited to take part in a research database. Before you accept or decline the invitation, it is important for you to understand why the research is being done and what it will involve. Please read the following information and discuss it with relatives, friends and your GP, if you wish. If there is anything that is not clear, or if you have any further questions, please ask us (our contact details are printed on page 3).

Take time to decide whether you would like to take part, or not.

You are being invited to take part in this research database because you have a rare neuromuscular disease known as Facioscapulohumeral Dystrophy (FSHD) and we are trying to get more information on patients, like you, with this condition.

The aim of this research is to establish a database, which will be computer record containing information about you and your condition. Having a computer database of patients with FSHD means that we can easily find groups of patients from all over the UK who may be able to take part in clinical trials to help develop new treatments. The

- Take your time to read through the whole page....

- When you reach the bottom of the page, please enter your initials in each text box to indicate you agree with each statement.
- If you do not enter your initials in each box, you will be unable to continue with your registration.
- Press the green 'continue' button to proceed.

If you feel that you have been treated unfairly throughout the research, or would like to comment on the conduct of any aspect of this research, please contact the Patient Advice and Liaison Service (PALS) 0800 0320202.

If you are concerned about the management of your personal data, a complaint may be lodged with the Information Commissioner's Office, UK: <https://ico.org.uk>.

Thank you for taking the time to read this information sheet.

Informed Consent

Please enter your initials "TU" in all of the text boxes below and click on the button "Continue" to give your consent.

I confirm that I have read and understand the information sheet dated 3rd April 2019 (version 1.6) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

By signing this document, I understand that I give consent for the storage of data on myself in the UK FSHD Patient Registry.

I understand that the storing of data will allow contact to be made with me if a suitable clinical trial becomes available.

However, I accept that allowing my data to be stored on this database does not mean I will automatically be entered into future clinical trials.

I understand that the data I provide may be used to inform future research outside of clinical trials and I am happy for it to do so.

I understand that the results from future research may not have any direct implications for myself or my family.

I confirm I am happy for specialists involved in my medical care to add relevant information to my database entry on my behalf.

I am happy to consent to be included in this registry.

[Legal Notice](#) [Data protection](#)

Step 7 – Select your doctor

- The next step is to select your doctor from the list. This should be your FSHD specialist, not your local GP or family doctor.

The screenshot shows the UK FSHD Patient Registry interface. On the left is a navigation menu with links: INFORMATION FOR PARTICIPANTS, INFORMATION FOR PROFESSIONALS, INFORMATION FOR RESEARCHERS, CONTACT US, USEFUL ORGANISATIONS, and LEAFLETS, NEWSLETTERS AND POSTERS. The main content area displays a green success message: "The patient has been added." Below this is the "Your doctor" section, which asks "Who is your doctor?" and provides a list of radio button options: Aleksandar Radunovic, Brierley, Charlotte - West Suffolk Hospital NHS Trust, Busby, Mark - Bradford, Channa Hewamadduma, and Charlotte Dougan.

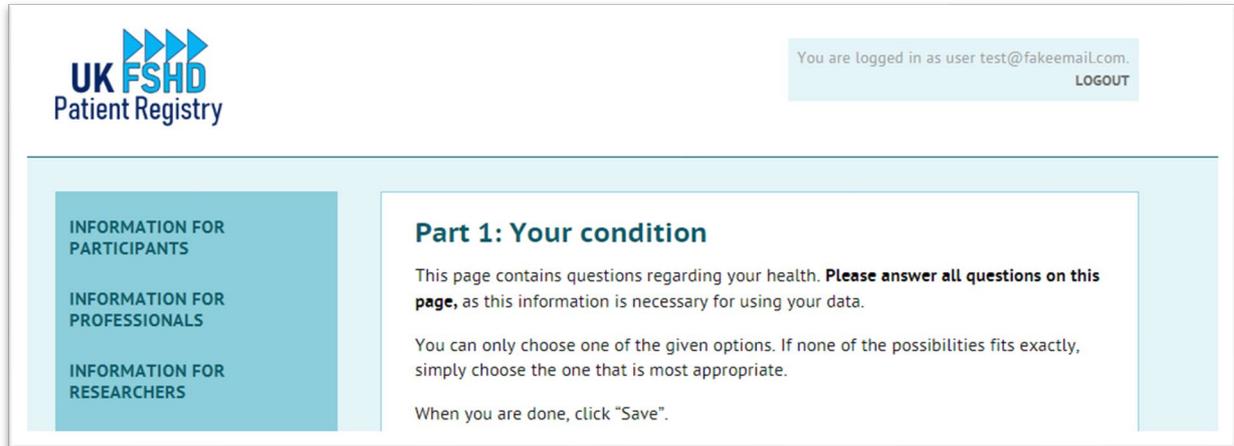
- If you don't see your specialist doctor on the list, please choose the 'no selection' option at the end of the list

This screenshot shows a dropdown menu for selecting a doctor. The visible options are: "Channa Hewamadduma - Bradford", "Willis, Tracey - Oswestry", and "No selection". Below the list are two buttons: a green "Continue" button and a red "Cancel" button. At the bottom right of the page, there are links for "Legal Notice" and "Data protection".

- If your doctor is not listed, please [contact the registry curator](#) with the full name of your specialist and which hospital they are based at, and they will be invited to join the registry.

Step 8 – Provide information about your / the patient’s condition

- At this point you have registered as a patient on the registry, but now we need to collect information about your / the patient’s condition.



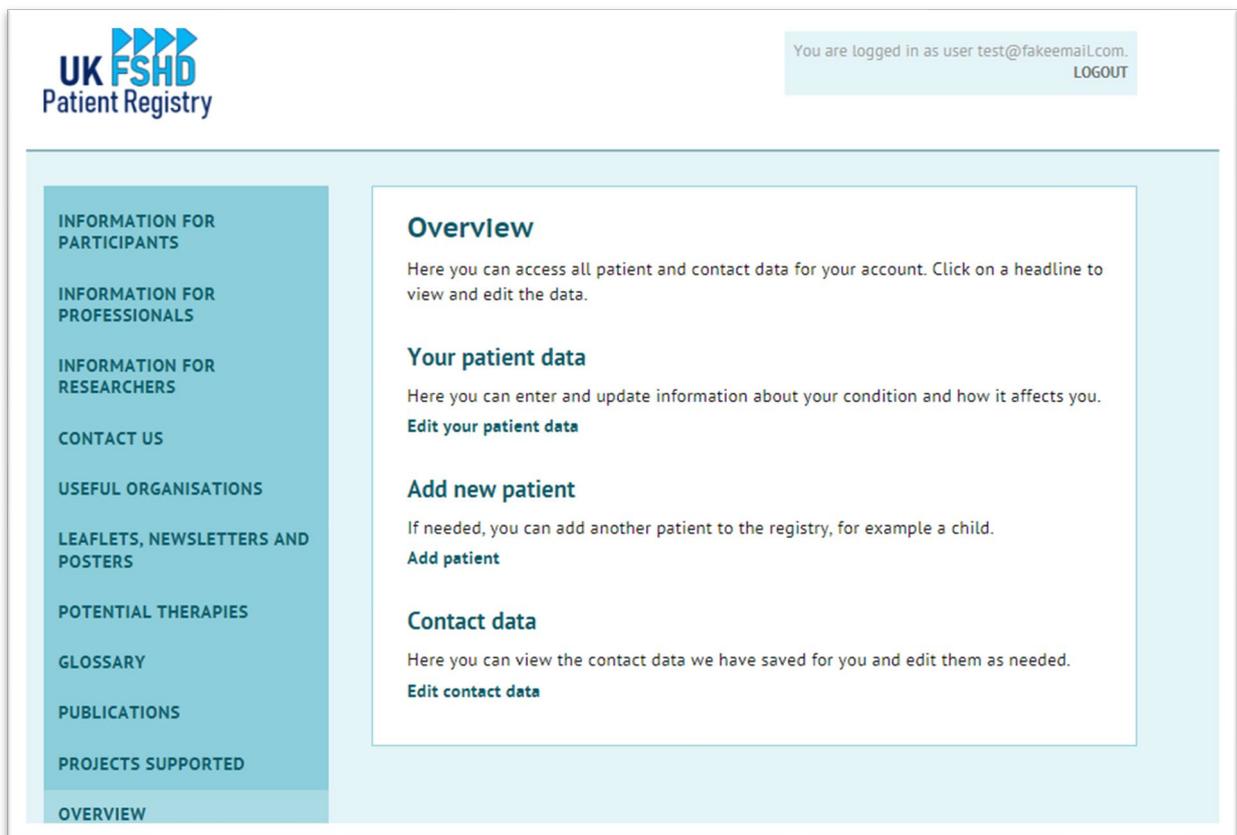
- These questions are split into 3 sections asking about your condition, your pain levels, and your wellbeing/quality of life.
- Please complete each page as thoroughly and honestly as you can, then click the green ‘save’ button at the end of the page to continue.
- If you need a break at any time you can logout and come back to this section by logging back in and clicking on ‘your patient data’ from the menu on the left of the screen



- Once you have completed section 3b ‘Your Quality of Life’ and clicked ‘save’, you have completed your registration and provided all the information we need for this patient for now.
- You will receive a reminder email in a years’ time to ask you to log back on to the website using the email address and password you entered in step 1. You can log in to update your answers to these questions as often as you like, but we ask that this is done at least annually
- You have now completed your registration! If you need to add another patient, please proceed to the next step.

Step 9 – Adding another patient

- This step is only required if you will be providing patient information for more than one patient (i.e., if you have two children with the condition, or if you are entering information for yourself as a patient and also for your partner as a patient). If an adult patient is willing and able, they should set up their own registration and complete the information themselves, however we appreciate this is not always possible.
- Ensure you are still logged in to the website (look for the ‘you are logged in as _____’ message in the top right of the screen. If you don’t see this, click ‘login’ from the menu on the left of the screen and enter the email address and password you used to register in step 1.
- Once you are logged in, click ‘overview’ from the left menu, then click ‘add new patient’

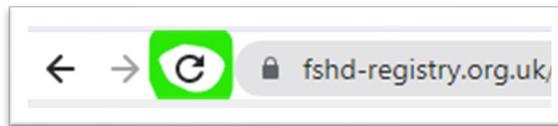


The screenshot displays the UK FSHD Patient Registry interface. At the top left is the logo, and at the top right, a notification states 'You are logged in as user test@fakeemail.com' with a 'LOGOUT' link. A left-hand navigation menu lists various categories, with 'OVERVIEW' highlighted. The main content area, titled 'Overview', provides instructions on accessing patient data and includes links for 'Your patient data', 'Add new patient', and 'Contact data'.

- Repeat steps 5 – 8 for this patient. Once this is complete, both patient names will then appear on the overview page so you can easily see whose information you are updating
- You can add as many patients as you want to by repeating this step, however please note you should only register patients for whom you are a parent or carer, and you will be responsible for keeping the information updated for any patients you have added.
- When a patient turns 16 years old, they will be required to complete the consent process again and given the option of creating their own user registration to take ownership of their patient record.

Troubleshooting

- If you see an error message at any point, please try to take a screenshot or a photograph of the screen if possible, and make a note of the time when the error occurred. This can help our IT team identify what has caused the problem.
- Please do not hesitate to contact the registry curator if you have any problems using the registry or are unsure what to do. You can [click here](#) to send them an email, or contact them by telephone on 0191 241 8640. The curator can guide you through the process step by step, or can even complete your registration for you over the phone if you are not confident using the website.
- If you do encounter an error message on the website, there are a couple of things you can try yourself that may resolve the issue without the need for any further steps...
 - Refresh the webpage. The refresh button usually looks like a circular arrow and will be somewhere near the website address (example circled in green below). It might look slightly different or be in a different position at the top of your screen depending on which web browser you are using. Clicking this button will re-load the page you were on so you may need to enter a small amount of information again.



- If refreshing the page does not work, try going back to the [registry homepage](#). You may need to log in again (check for the message in the top right of the screen that will appear if you are already logged in).
- When you are logged in, you can click 'overview' from the left menu to navigate back to the page you were on when the error happened.

Problems logging in?

- If you have any problems with logging in to the registry, please do not try to register again as this can lead to duplicate records. Please [contact the registry curator](#) who can help identify and resolve the issue.
- If you are unsure if you have registered previously or not, please [contact the registry curator](#) who can check if you have any historical or partially completed registrations.

If you have any questions, comments, or feedback, or would like more information about anything to do with the UK FSHD Patient Registry please [get in touch with the registry curator](#) who is on hand to help.