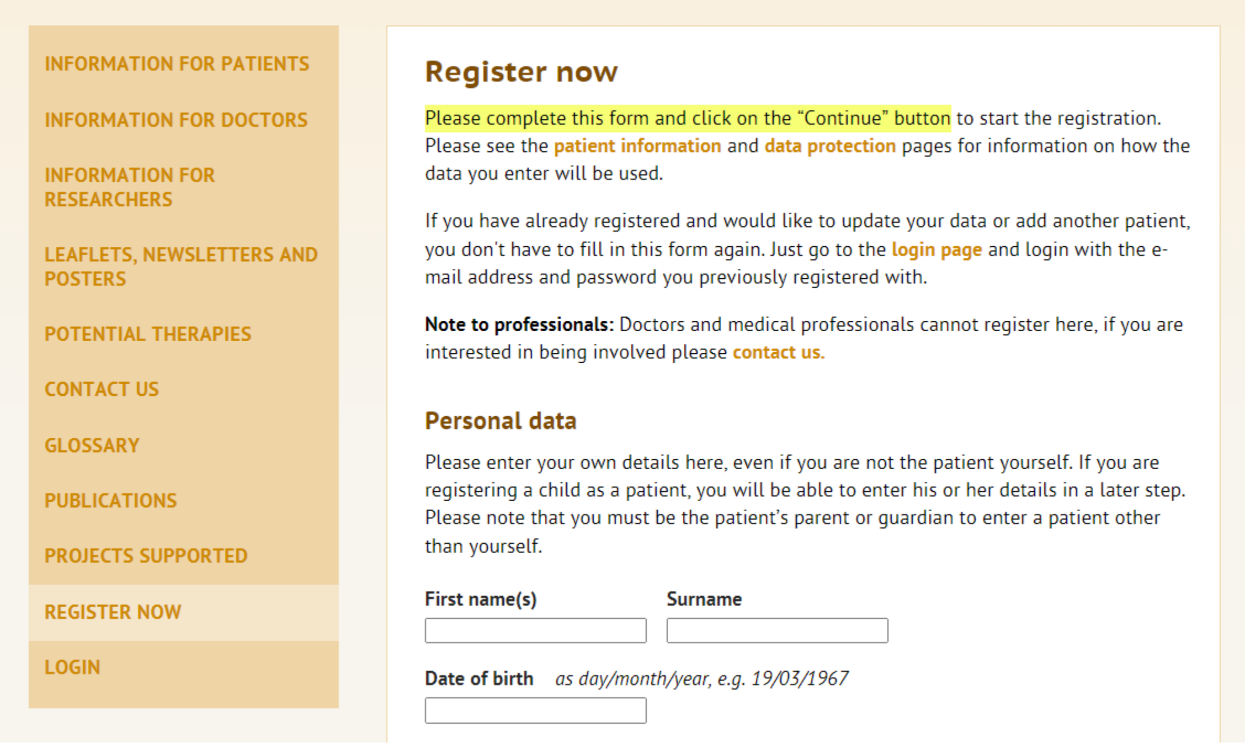
UK Myotonic Dystrophy Patient Registry Registration User Guide

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

Contents

Step 1 – Setup your user account

- Go to the registry website - https://www.dm-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.



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.

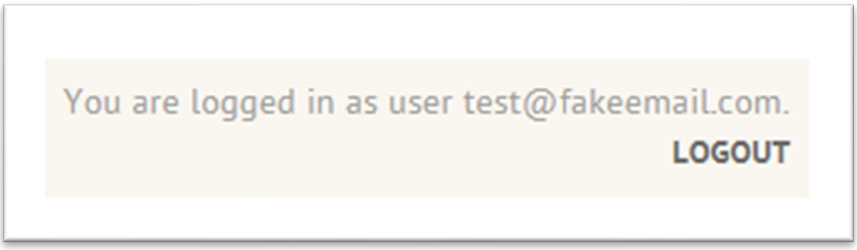
First name(s)

Surname

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

Step 2 – Confirm your details

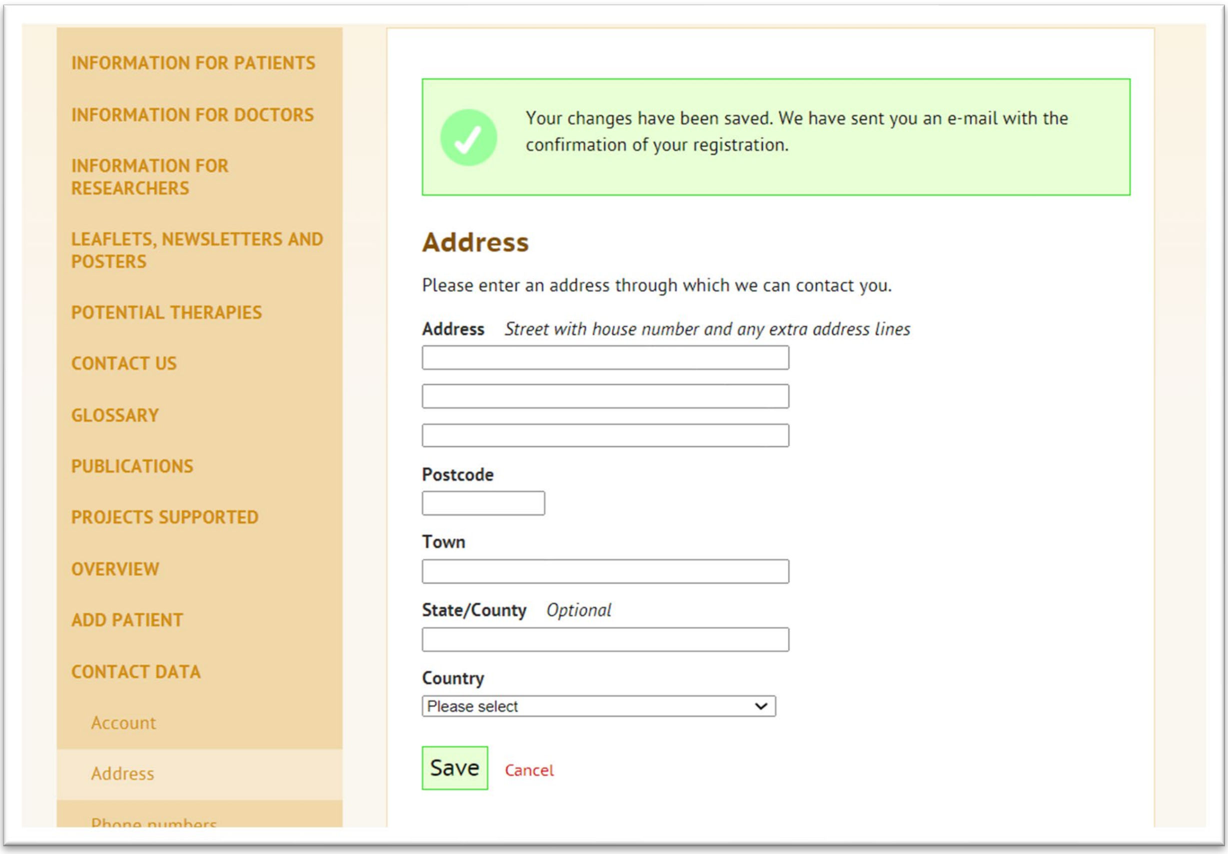
- Check that you have entered your name, date of birth, sex and email address correctly.
- Press the yellow ‘back’ button if you need to make any changes (don’t use your web browser’s back button).
- If you are happy your information is correct, press the green ‘continue’ button
- After pressing ‘continue’,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



You are logged in as user test@fakeemail.com.

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.



Your changes have been saved. We have sent you an e-mail with the confirmation of your registration.

Address

Please enter an address through which we can contact you.

Address *Street with house number and any extra address lines*

Postcode

Town

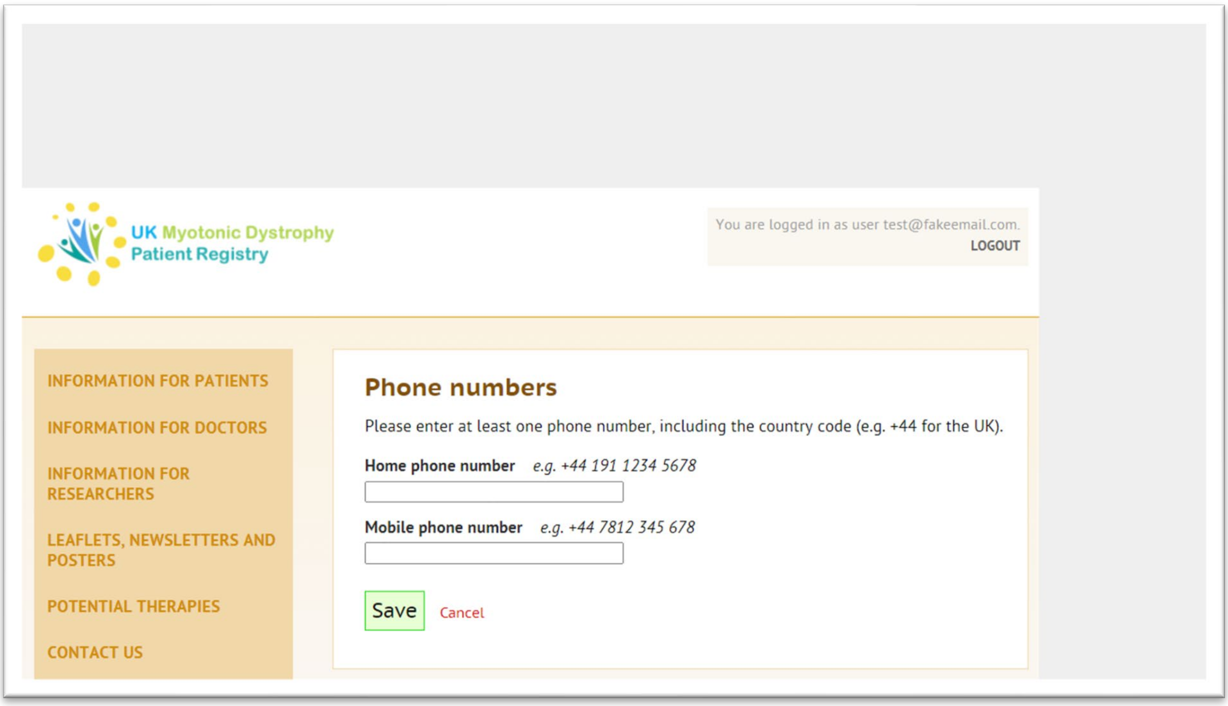
State/County *Optional*

Country

Please select

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.



You are logged in as user test@fakeemail.com.

Phone numbers

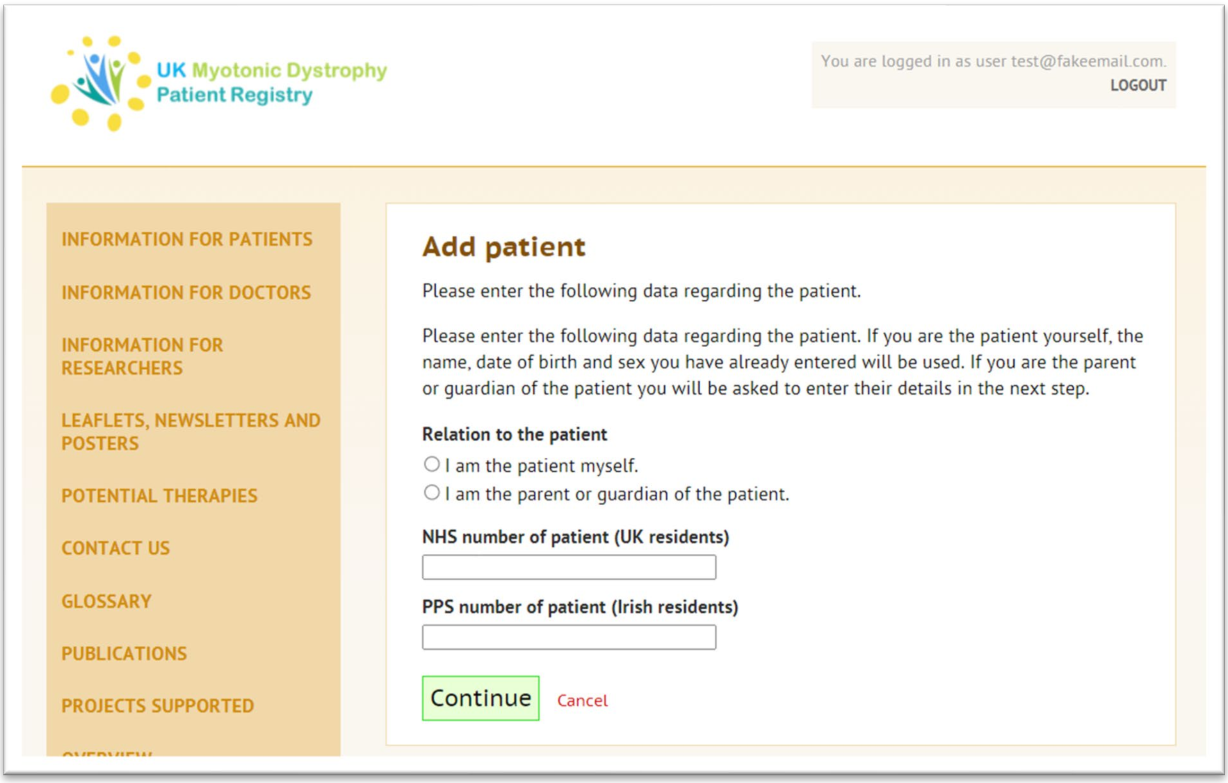
Please enter at least one phone number, including the country code (e.g. +44 for the UK).

Home phone number *e.g. +44 191 1234 5678*

Mobile phone number *e.g. +44 7812 345 678*

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.



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.

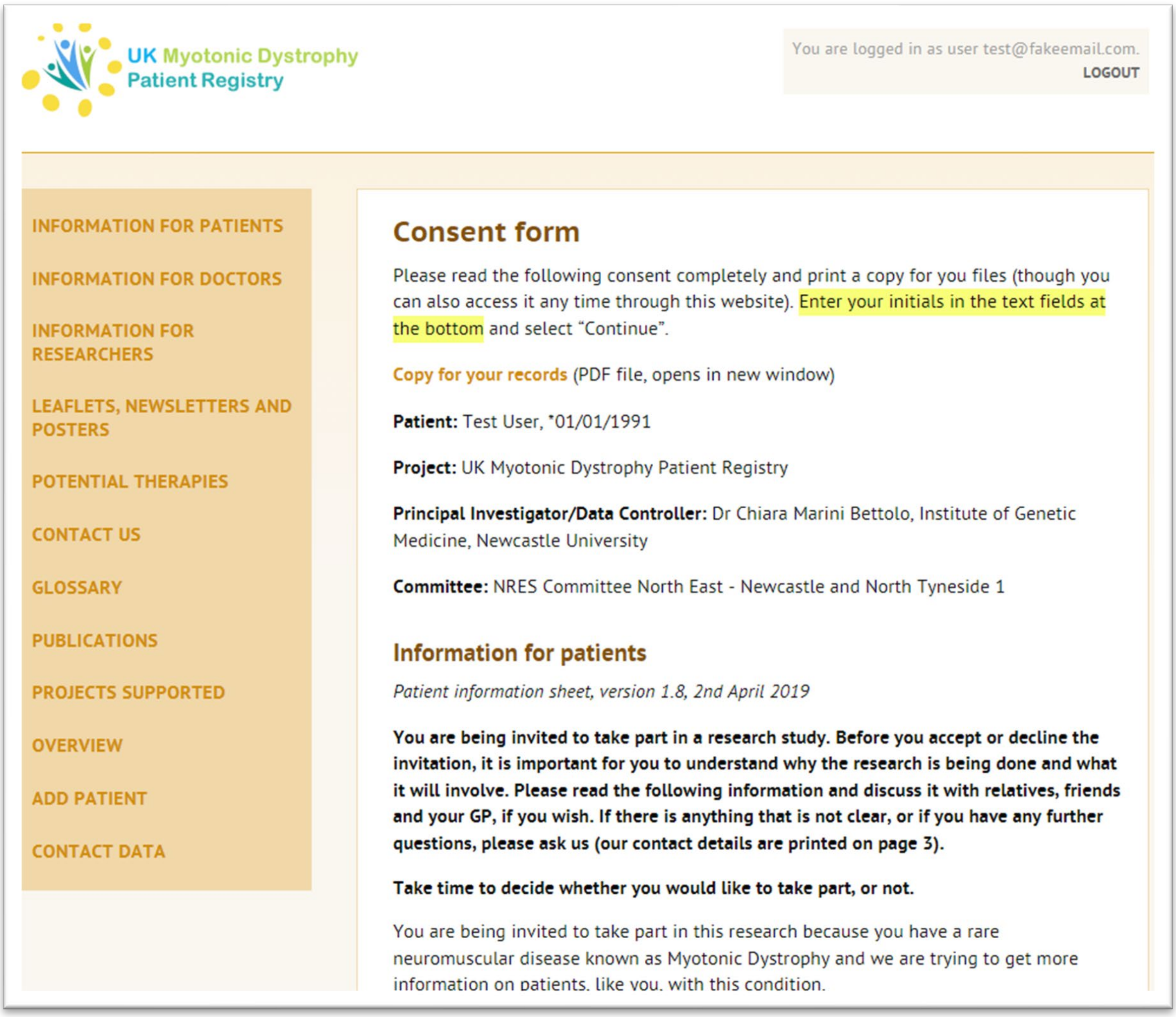
○ I am the parent or guardian of the patient.

NHS number of patient (UK residents)

PPS number of patient (Irish residents)

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.



Consent form

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 User, *01/01/1991

Project: UK Myotonic Dystrophy Patient Registry

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

Committee: NRES Committee North East - Newcastle and North Tyneside 1

Information for patients

Patient information sheet, version 1.8, 2nd April 2019

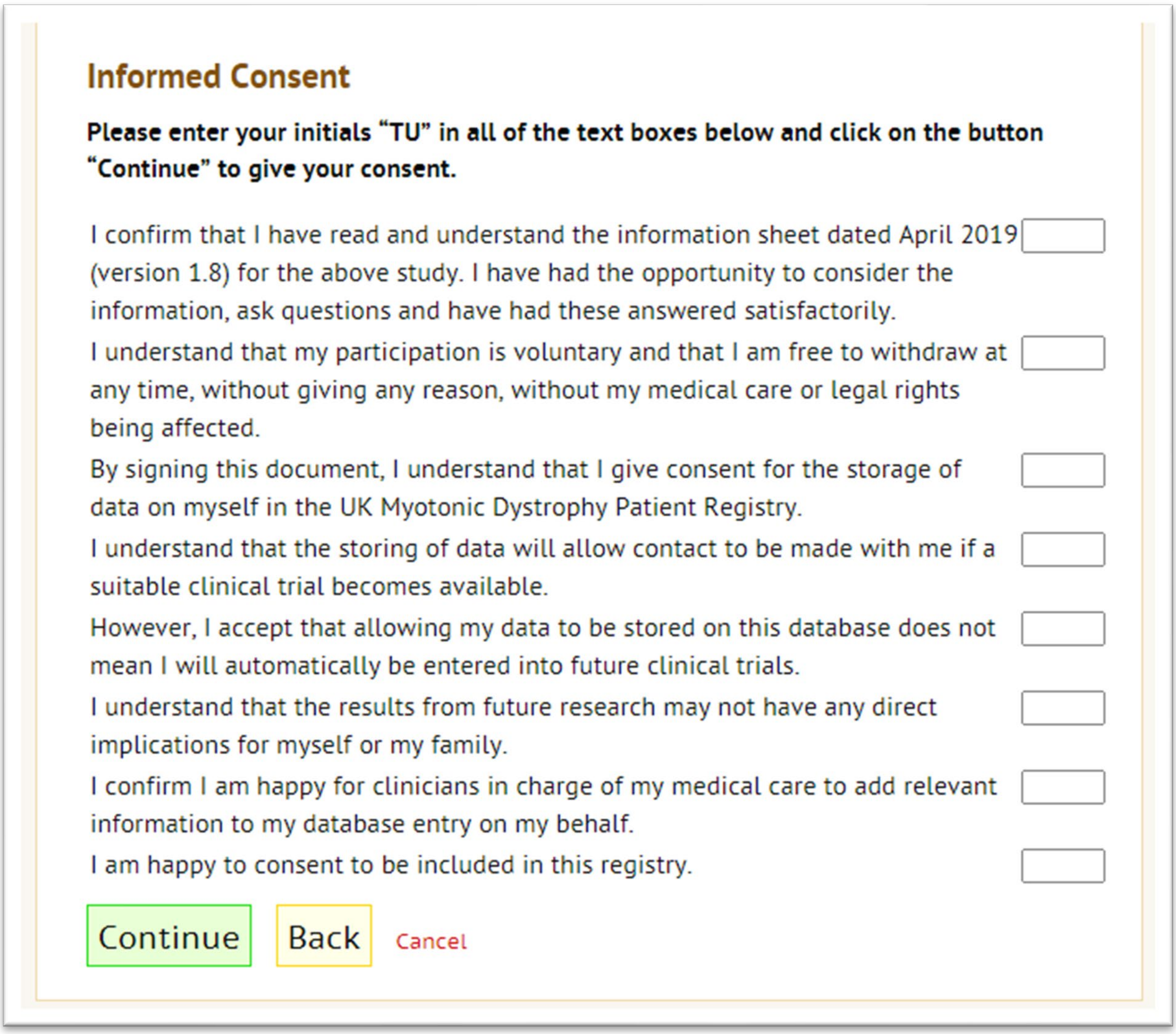
You are being invited to take part in a research study. Before you accept or decline the invitation, it is important for you to understand why the research is being done and what it will involve. Please read the following information and discuss it with relatives, friends and your GP, if you wish. If 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 because you have a rare neuromuscular disease known as Myotonic Dystrophy and we are trying to get more information on patients, like you, with this condition.

- 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.



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 April 2019 (version 1.8) 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 Myotonic Dystrophy 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.

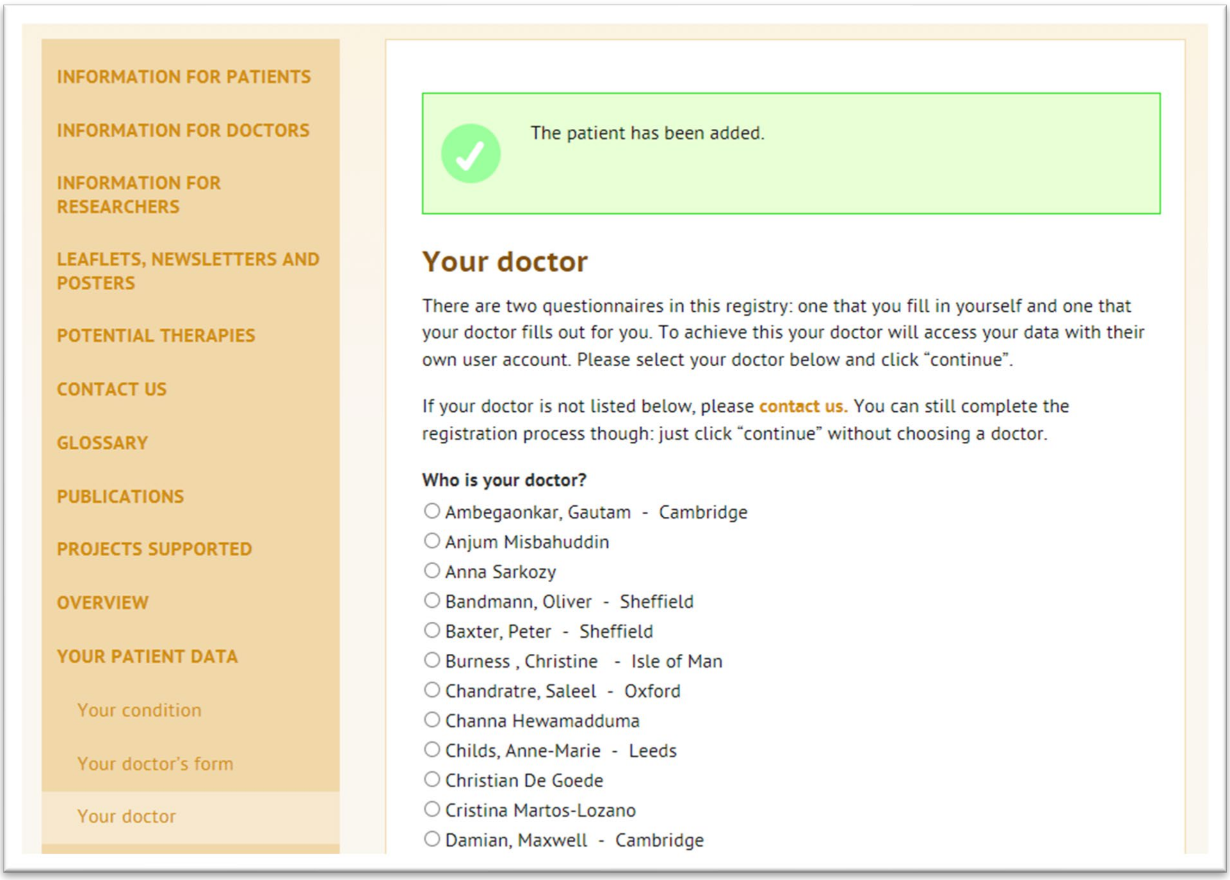
I understand that the results from future research may not have any direct implications for myself or my family.

I confirm I am happy for clinicians in charge of 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.

Step 7 – Select your doctor

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



✓ The patient has been added.

Your doctor

There are two questionnaires in this registry: one that you fill in yourself and one that your doctor fills out for you. To achieve this your doctor will access your data with their own user account. Please select your doctor below and click "continue".

If your doctor is not listed below, please **contact us**. You can still complete the registration process though: just click "continue" without choosing a doctor.

Who is your doctor?

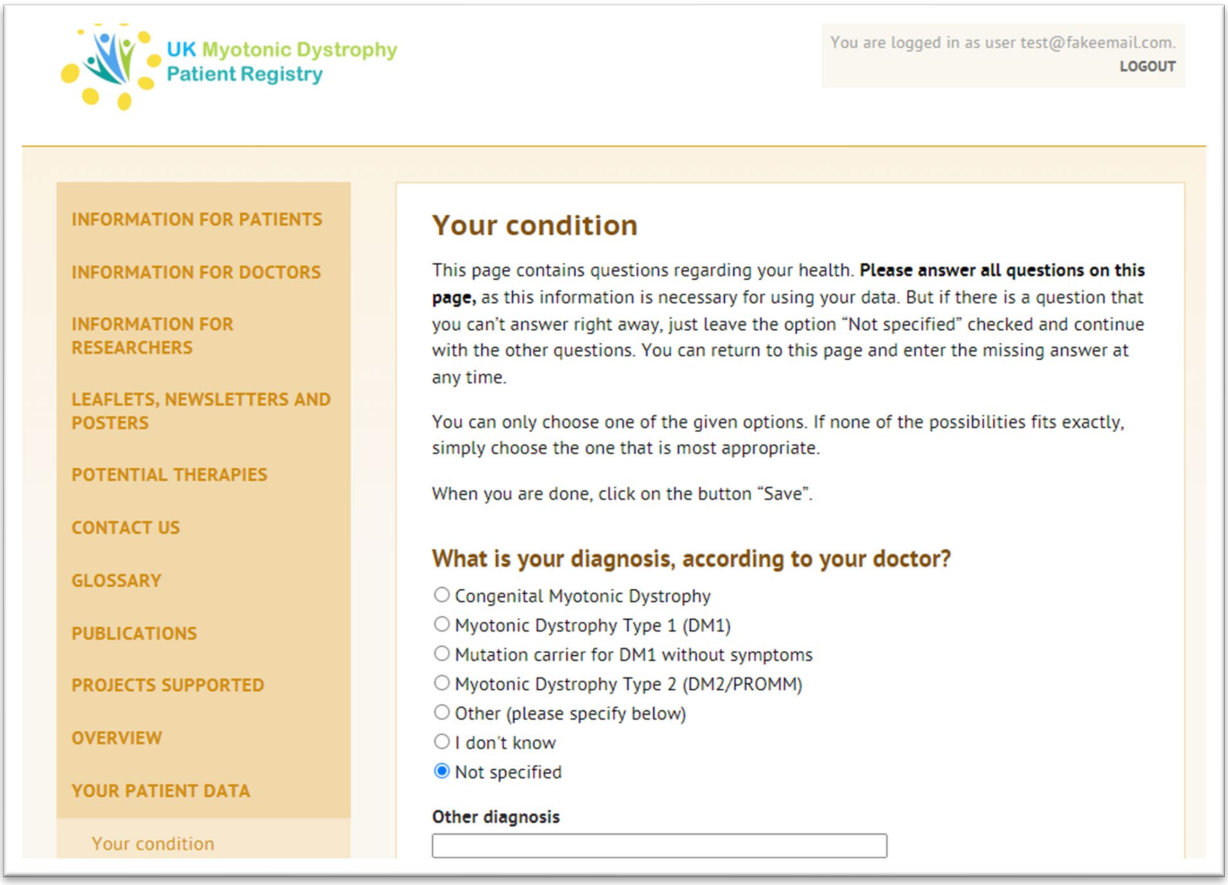
○ Ambegaonkar, Gautam - Cambridge
○ Anjum Misbahuddin
○ Anna Sarkozy
○ Bandmann, Oliver - Sheffield
○ Baxter, Peter - Sheffield
○ Burness , Christine - Isle of Man
○ Chandratre, Saleel - Oxford
○ Channa Hewamadduma
○ Childs, Anne-Marie - Leeds
○ Christian De Goede
○ Cristina Martos-Lozano
○ Damian, Maxwell - Cambridge

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

- 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.



Your condition

This page contains questions regarding your health. **Please answer all questions on this page,** as this information is necessary for using your data. But if there is a question that you can't answer right away, just leave the option "Not specified" checked and continue with the other questions. You can return to this page and enter the missing answer at any time.

You can only choose one of the given options. If none of the possibilities fits exactly, simply choose the one that is most appropriate.

When you are done, click on the button "Save".

What is your diagnosis, according to your doctor?

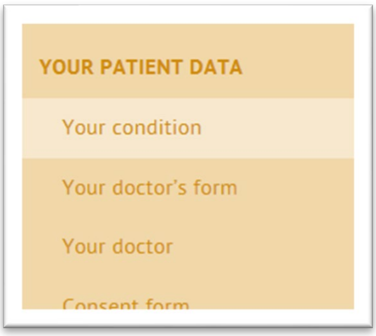
○ Congenital Myotonic Dystrophy
○ Myotonic Dystrophy Type 1 (DM1)
○ Mutation carrier for DM1 without symptoms
○ Myotonic Dystrophy Type 2 (DM2/PROMM)
○ Other (please specify below)
○ I don't know
● Not specified

Other diagnosis

- 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 the questionnaire in the 'your condition' section 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

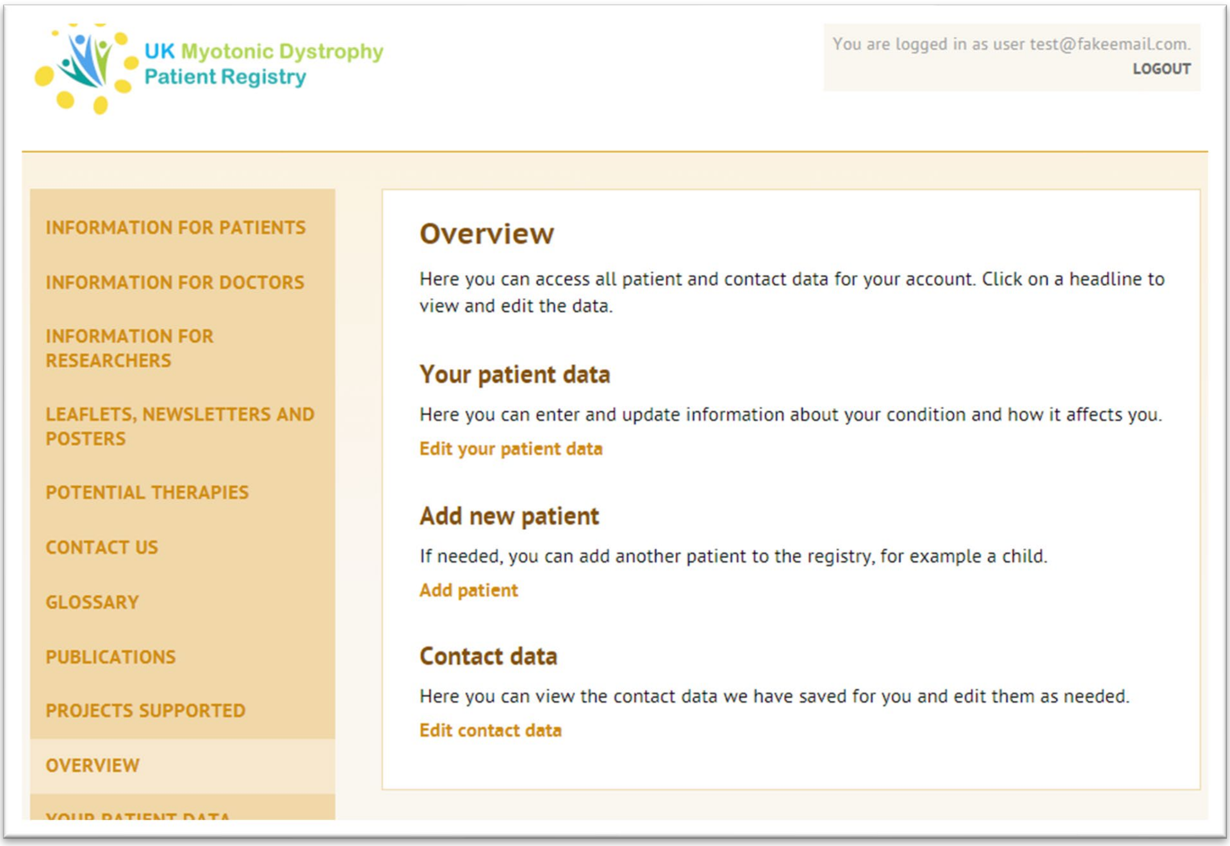
- You have now completed your registration! If you need to add another patient, please proceed to the next step.

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'



Overview

Here you can access all patient and contact data for your account. Click on a headline to view and edit the data.

Your patient data

Here you can enter and update information about your condition and how it affects you.

Add new patient

If needed, you can add another patient to the registry, for example a child.

Contact data

Here you can view the contact data we have saved for you and edit them as needed.

- 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.

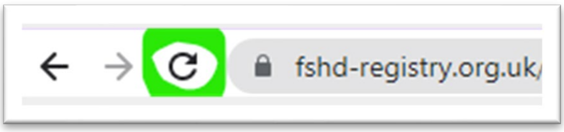
- When a patient turns 18 years old, they will be required to complete the consent process again and given the option of creating their own user registration to take ownership of their patient record.

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.



fshd-registry.org.uk/

    - 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 Myotonic Dystrophy Patient Registry please get in touch with the registry curator who is on hand to help.