

MCDS-Therapy Privacy policy

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This privacy statement provides information about the personal information that the MCDS-Therapy team collects through its website www.mcds-therapy.eu and its non-research activities. It details the ways in which we use that personal information.

Any data related to clinical research is handled under a different policy. Find out more about it here.

MCDS-therapy may change this policy at any time in line with legislative changes or changes to its practices. Please check our website from time to time to ensure you are aware of any changes.

IN THIS POLICY DOCUMENT:

"we" or "MCDS-Therapy" means the MCDS-Therapy consortium;

"you" means any person(s) about whom we collect non-personal and/or personal information.

Our Privacy Principals

MCDS-Therapy adheres to the Principles of the General Data Protection Regulation (GDPR). We collect data for two main reasons:

1. To allow us to monitor the use of our website and improve its functionality and the user experience.
2. To allow us to engage directly with those individuals who are interested in learning more about MCDS-Therapy and our progress through our online newsletter.

As the project develops, we may begin to run events and webinars for the MCDS-Therapy community. This will require us to collect additional data to deliver these projects effectively. We will update this privacy policy to reflect these activities once they begin, and we will always notify you when we are collecting data or get your consent to do so.

If we contact you, we aim to only provide you with information that you have asked for by consenting to be part of our mailing lists. You can opt out of receiving information at any time.

We will only collect data from you that is needed to deliver our work and aim to keep that data for a limited period. We will never sell your data to a third-party organisation, and never share your information for marketing purposes. We will only pass it on to a third-party organisation where it is necessary to deliver our work. For example, we use the third-party platform MailChimp to deliver our newsletter, and they hold the necessary data. We will make it clear when we need to do this.

MCDS-Therapy will take all reasonable care to protect your personal information through secure working practices and processes. In line with the GDPR, we will provide you with a summary of information we hold about you upon request and will remove your information from our records upon request if we are not legally required to hold it.

Your data and the MCDS-Therapy consortium

MCDS-Therapy is a consortium of 11 organisations funded to deliver a clinical trial to test the efficacy of carbamazepine in MCDS. One of our consortium members, the rare disease charity Findacure, is responsible for outreach and communication in the project. Findacure will act as the data controller for the MCDS-Therapy website. Representatives of the University of Newcastle, which is the host organisation of the project coordinator, and Finovatis, the organisation in charge of project management, may both have access to your data if necessary. Both organisations will follow the principals outlined in this document when doing so. We will not share your data with other consortium members without first securing your consent.

Any MCDS-Therapy collaborators who have access to your data will not use it for any of their other activities beyond MCDS-Therapy. Any details they store will be held independently of any other personal data they store so that you will not accidentally receive unsolicited information from those organisations.

Data related to the clinical trial itself is not associated with the MCDS-Therapy website and is governed by different policies in line with the appropriate legislation.

The following information provides a detailed breakdown of all the data we collect, how we hold it and use it, and the reason behind collecting it. If you would like to learn more about our privacy policy or our work, please contact us using info@mc ds-therapy.eu at any time.

What information do we collect?

We currently collect limited information. In general, we collect and store information about those who engage with the MCDS-Therapy website, and those interested in joining our newsletter. We collect this data to deliver information about our project to you, either by improving our website, or through the mailing list. We will secure explicit consent to contact you directly, and to share your information with any additional party.

1. Your browsing

LAWFUL BASIS - LEGITIMATE INTEREST

We collect basic information about the users of our website. Whenever you access our website or download information, the web server automatically records the following information: the date and time you accessed our website; how long you were on the site; your internet domain name; and the internet browser you use.

Some information may be collected when you use our website, including information such as your IP address. We also automatically receive and record information on our server logs in order to use services like Google Analytics. This information is used to help us improve our website, to increase traffic to our site, and raise the profile of the MCDS-Therapy project.

To make use of Google Analytics, our website uses cookies. Any YouTube videos embedded in our website also make use of cookies. A cookie is a series of characters that is generated by our website and stored on your computer. The cookie does not collect or contain personal information about you but allows you to keep logged in and records your use of our website. The cookie does not track your movements on other websites. YouTube may collect personal data through cookies used on their website. To view their privacy policy, [click here](#). You can adjust the settings on your computer to decline any cookies if you wish. This can be done by activating the 'reject cookies' setting on your computer.

Comments

When visitors leave comments on the site we collect the data shown in the comments form, and also the visitor's IP address and browser user agent string to help spam detection.

An anonymized string created from your email address (also called a hash) may be provided to the Gravatar service to see if you are using it. The Gravatar service privacy policy is available here: <https://automattic.com/privacy/>. After approval of your comment, your profile picture is visible to the public in the context of your comment.

If you leave a comment on our site you may opt-in to saving your name, email address and website in cookies. These are for your convenience so that you do not have to fill in your details again when you leave another comment. These cookies will last for one year.

If you leave a comment, the comment and its metadata are retained indefinitely. This is so we can recognize and approve any follow-up comments automatically instead of holding them in a moderation queue.

2. Your contact with us

LAWFUL BASIS - LEGITIMATE INTEREST

If you contact MCDS-Therapy by telephone, e-mail, or by letter, we retain a record of your contact to help us respond to enquiries. We only collect this information if you provide it to us and we do not hold your information for longer than is necessary.

MCDS-Therapy email accounts are provided through our website, where all email messages and addresses are stored. All emails and associated details may be retained for a period of up to 3 years before being deleted. If you email a member of the consortium on an email that does not use the @mcDs-therapy.eu domain name, that email will be sorted on a different server, and will not be subject to this privacy policy.

Regardless, all members of MCDS-Therapy will endeavour to treat your data with confidentiality and respect.

3. MCDS-Therapy mailing list

LAWFUL BASIS - CONSENT

MCDS-Therapy currently has a single mailing list – The MCDS-Therapy Community mailing list. This is managed by Findacure and hosted in MailChimp. Our mailing list is periodic and open for anyone to join. It requires your consent for us to contact you and hold your data. MCDS-Therapy's mailing list is administered through MailChimp, who stores the name and email address of all individuals on

the mailing list and track information on engagement with the messages sent. MailChimp's privacy policy can be viewed [here](#). The mailing list is joined through an online GDPR compliant consent form, which is accessed through our website. Only individuals who specifically opt in to receive a newsletter, either through our [sign up](#) forms or a direct request, will receive messages and have their details stored. You may choose to stop receiving our mailing list at any time through a link provided at the end of all mailing list emails, or by contacting us at info@mclds-therapy.eu.

Findacure holds a digital copy of the MCDS-Therapy Community mailing list on their server, including records of consent. This acts as a back-up mailing list, and a historical record of consent.

In the future we may use short term project specific mailing lists – these allow us to provide information about a specific project to those involved with it. If you sign up for the project we will add you to one of these lists in order to fulfil our obligation to you, but will not contact you about other work, or hold your data longer than necessary. We will always notify you if you are being added to such a mailing list as part of a project you have chosen to join.

4. Focus groups and community research projects

LAWFUL BASIS – CONSENT

MCDS-Therapy plans to run a series of community research projects, to better understand the impact of MCDS on patients and families. If you volunteer to take part in one of our research projects, we will secure your consent to store your contact information and any information we collect from you. This may include recordings of interviews and focus groups, or simply written notes from our discussions. We will not identify individuals within any resultant publications without securing explicit consent first. We will only contact you about the project, the results of our research, or similar research opportunities in the future.

5. Expense claims

LAWFUL BASIS – ADMINISTRATION

In the event that MCDS-Therapy reimburses expenses for an individual attending or assisting with an event or project, we will collect personal data in order to process such payments. We will securely store this information in order to meet the needs of our accounting processes.

6. Social media

MCDS-Therapy is active on Facebook and Twitter. We do not collect data from these social media sources, though we will endeavour to answer messages directed to us through these sources. All

messages sent to MCDS-Therapy in this regard are governed by the privacy policies of the chosen platform.

How long do we keep your data?

MCDS-Therapy is a five-year project. We will keep your information for the project's duration unless we specify otherwise. Your data will be retained securely.

Your rights

You may ask us to destroy any of your personal information that we hold so that you receive no further information or contact from us. In this circumstance, if you are currently registered for an event or project we will contact you to confirm your wish to continue involvement, and if so remove your data subsequent to completion of the project.

If you have taken part in a community research project, your research information will be kept for 3 years or as otherwise detailed to you in the project information sheet, after the end of the project then destroyed securely. If you are involved in MCDS-Therapy's clinical research this data will be handled separately. Please notify us if you would like to be removed from those databases too, or refer to your patient information sheets to find out the best approach to do this.

You may ask to have a copy of the information we hold about you and/or your organisation and to amend, update, add to or delete it at any time. Should you wish to restrict the use of your personal information, please contact us by email at info@mcds-therapy.eu or in writing at the address supplied on the MCDS-Therapy website.

Who has access to your information?

As detailed in "Our Privacy Principals" MCDS-Therapy is a collaborative consortium. Three organisations will have access to your information by default: Newcastle University, Finovatis, and Findacure. Only Findacure will have day-to-day access and will act as the data controller. Specific members of staff from these organisations will have access to your personal information – but this will be limited to those staff members directly involved with MCDS-Therapy.

If you provide information through involvement with a specific event or project, that information will also be shared with any organisations that are listed as a project collaborator or co-organiser.

Finally, some information may be shared with event venues to ensure that your needs are met on the day.

As detailed above, we may use third parties to provide services on our behalf, including MailChimp. Those parties only collect and hold the information they need to deliver the service, though data is held in accordance with their own privacy policies.

If you have taken part in a community research project, we will not tell anyone you have taken part and we will not share your information with any third party without your consent. Any collaborators with access to your information will be explicitly named when you give your consent.

We may disclose personal information if we receive a complaint about any content you have posted or transmitted to or from our site, if required to do so by law or if we believe that such action is necessary to protect and defend the rights, property or personal safety of MCDS-Therapy, any child or vulnerable adult, our staff, any visitor or third party. Except as indicated above we will not use or transfer this data to any third parties without your explicit consent permission.

Publications

We publish information leaflets and newsletters for our subscribers and those that interact with MCDS-Therapy. From time to time these will contain personal information about our MCDS-Therapy community, such as the stories of individual members. We will never publish any information or an explicitly identified image without clear consent from those concerned. We might use quotes from you in academic publications and conferences but will always ask your permission if anything in the quotation is identifiable.

Can you access the information we hold about you?

Yes, you have the right to access information stored about you by MCDS-Therapy. You need to write to us at the address below or email us at info@mcds-therapy.eu. We will then provide you with the following information:

- € What personal data is stored
- € The purposes for which your data is being processed
- € Who has access to your data

What security measures do we have?

We have implemented technology and policies to protect your privacy from unauthorised access and improper use and will review these measures on a regular basis. While we cannot ensure or guarantee that loss, misuse or alteration of data will not occur, we shall endeavour to prevent this.

Links to other websites

The MCDS-Therapy website (www.mcds-therapy.eu) may contain links to selected websites which we feel may be of interest. Please note that once you use one of these links to leave our website, we do not have any control over that other website. Please exercise caution and refer to their privacy policy and/or terms & conditions of use as we cannot be held responsible for the protection or privacy of any information you provide to a third party.

Any questions about privacy?

If you have any questions or concerns about how we protect your personal information, please contact us.

E-MAIL

info@mcds-therapy.eu

TELEPHONE

Findacure: +44 (0)1223 222767

POST

Findacure c/o AdviceHub

66 Devonshire Road

Cambridge

CB1 2BL