

MCT8 Deficiency Caregiver Study Privacy Policy

In this Privacy Policy "we", "us", and "Vitaccess" refer to Vitaccess Ltd. When we talk about "you", we mean adult caregivers of people with monocarboxylate transporter 8 (MCT8) deficiency taking part in the study.

Your privacy is very important to us at Vitaccess Ltd.

We provide this policy to explain our information practices, including how Vitaccess collects and manages personal data, your statutory rights, and the choices you can make about the way your information is collected and processed.

This policy provides you with a clear explanation of when, why, and how we collect and process your personal data. It is not intended to override any rights you have under applicable data privacy laws.

To make this policy easy to find, it is available on the study homepage.

We strongly encourage you to read this policy and make sure you fully understand it.

About the MCT8 deficiency caregiver study

Welcome to the MCT8 deficiency caregiver study.

This is a research study about MCT8 deficiency.

The aim is to learn about the economic burden of MCT8 deficiency and its impact on health-related quality of life, as reported by caregivers, so we can help improve the lives of people affected by the condition.

Who is running the study?

We are Vitaccess Ltd, a UK-based research company registered in England and Wales (company number 10642948).

We are running this study with the study sponsor, Egetis Therapeutics, a pharmaceutical company based in Sweden. We are partnering with a technology company, Global Perspectives, to host the survey for the study and issue Amazon vouchers. For data protection purposes, Egetis Therapeutics is the data controller for the study and we are the data processor.

This means that Egetis Therapeutics decides on the goal for the data collection and processing, and how the processing is done – processing means every operation performed on personal data, such as collection, storage, retrieval, analysis, and erasure. Data controllers are the owners of the data. They also must ensure they have a legal basis in place, which is the lawful reason for collecting and using your data.

A data processor processes personal data on behalf of the data controller and does not own the data. The data processor operates under the legal basis of the data controller.

We may also act as a data controller for some of the data collected via the survey. We are the data controller for any data that we collect for our own reasons, rather than as part of the study. For more details, see the "Why is my data being collected?" section of this policy.

Why is my data being collected?

We collect your data to run the study:

- to find out more about MCT8 deficiency and the impact it has on the caregivers of people who have it.
- for study admin, like creating an account for you and contacting you about the study.

We might also use your data for other reasons:

- to track your participation in the survey, to check it is being used properly, or to look after the survey and our systems.
- to see how people participate in the survey so we can make it easier to use, and to help us design studies like this in the future.
- to help protect or act on Egetis Therapeutics' or our legal rights, or to follow the law.

What data is collected?

We collect personal data about you, which may include:

- age
- email address
- country of residence
- any other personal data you may provide to us during your time in the study.

We may also collect sensitive data about you or the person you provide care for. For example:

- approximate annual gross income
- health and MCT8 deficiency data. This might include data about the person you provide care for, and the impact of caregiving on your life and wellbeing
- demographic data.

How will my data be collected?

We collect your data when you participate in the survey.

We collect data that you enter directly. This includes data you enter when you register your interest for the study, complete the eligibility questions, or take part by filling in the survey.

We may also collect data about you that you do not enter directly. This includes data about how you participate in the survey, for example, how long it takes you to answer questions, or whether you miss out any questions. We use this data to make the survey easier to use.

What are the lawful reasons for collecting my data?

We will only use your personal data for the purposes set out in this policy. In line with data protection law, we must have lawful reasons for collecting and using your data. These include:

- **your consent.** When you register for the study, we ask for consent from you, on Egetis Therapeutics' behalf, to use your data for the study. We only use your data for the study if we receive consent. If you decide to withdraw consent, please [contact us](#).
- **we have a legitimate interest.** We might have legitimate reasons for using your data on behalf of Egetis Therapeutics. These include study admin, tracking proper use of the survey, and protecting Egetis Therapeutics' legal rights. We might also have our own legitimate business reasons for using your data. These include looking after the survey and our systems, and protecting our own rights.

- **we have a legal obligation.** In some circumstances we might need to collect or share your data to follow the law or to help Egetis Therapeutics follow it.

How will my data be stored and kept secure?

We have appointed a Data Protection Officer, who is responsible for overseeing use of personal data by Vitaccess. You may contact the Data Protection Officer with any queries or concerns about our use of your data (contact details are provided below).

We keep your data secure and confidential. Before we share anything with Egetis Therapeutics, we will separate the data we use for research from the personal data that could identify you. This means that nobody looking at the research data can work out who you are without needing other data to reidentify you – a process known as pseudonymization.

In exceptional circumstances, like for safety or data integrity reasons, we may use a key to link the data back together to re-identify you. For example, if we spot a health risk in your data and need to contact you about it.

We will not use your name, or other data that could identify you, in presentations or reports. However, we may publish grouped, anonymized data from the study.

We will keep your data for the duration of the study, and for 5 years afterwards. We might also keep anonymized records about you after the study, for example, to help improve the survey for future research.

Once we no longer need your data, for the reasons we have described, we will erase or anonymize it by removing the personal data that could identify you.

If you leave, or we remove you from the study, we won't collect any new data about you, but we will keep the data that we have already collected. If you would like us to anonymize your data (remove identifying information) or request that we erase your data, please [contact us](#).

Who will have access to my data?

Personal data are only processed for internal purposes, except in exceptional cases, namely when we are obliged to do so based on a statutory provision or a decision of the court or supervisory authority, or if this is necessary in the interests of the prevention or prosecution of criminal offenses, such as fraud or deception.

Where permitted by local data protection laws, we may disclose or otherwise allow others access to your personal data in response to a legal request, such as a subpoena, legal proceedings, search warrant, or court order, or in compliance with applicable laws, if we believe in good faith that the law requires us to do so, with or without notice to you.

If warranted, we may also allow access to this information in special emergencies where physical safety is at risk. We reserve the right to disclose any personal data or other information obtained from or about you to third parties in connection with a merger, acquisition, bankruptcy, or sale of all or substantially all of our assets, to the extent that this is necessary for the process.

The personal data collected by us may be transferred for the purposes mentioned above (purpose of processing and legal grounds) to any third parties we subcontract for all or part of this processing. This may include hosting providers and server co-location services, communications and content delivery networks, data and cyber security services, fraud

detection and prevention services, web analytics, email distribution and monitoring services, session recording and remote access services, performance measurement data optimization and marketing services, content providers, our legal and financial advisors, and any other relevant roles. Note that we will never sell your personal data to a third party.

In the event of transfer of personal data to a country outside of the European Economic Area (EEA), we systematically ensure the application of an adequate level of protection to personal data by means approved by applicable data protection legislation, like that in the UK.

Where appropriate, we may share your data with the following people and organizations:

Group	Location	Reason	Is personal data shared?
Vitaccess	UK	To run the study	Only with a small team who are managing the data
Our technology providers (Global Perspectives)	Worldwide	To help us store and analyze the data and to provide compensation to participants	Yes
Egetis Therapeutics	Sweden	To learn about MCT8 deficiency and its impact on caregivers	Not usually, but as the data controller Egetis Therapeutics does have a legal right to access identifying information
Ethics committees	The UK, US, Canada, France, Netherlands, Spain, Australia, Italy, and Germany	To review the study to protect the safety and rights of participants	Only if needed to investigate a complaint
Legal authorities	The country where you live	To make sure we are running the study properly	Yes, if requested

What are my legal rights?

Data protection law gives you rights regarding your data:

- **your right to be informed.** To know (a) the name and address of the data controllers; (b) the source of your personal data; (c) whether your data is being processed; (d) for what purpose your data is used; (e) the purposes, legal basis, and

methods of processing; and (f) the entities or categories of entity to which your personal data may be transferred.

- **your right to access.** To request that we provide you with a copy of your personal data that we hold. This right of access is not absolute, for example if it affects the rights and freedoms of others or is manifestly unfounded or excessive.
- **your right to withdraw consent.** To withdraw your consent at any time. This does not affect the lawfulness of any processing that you had previously consented to.
- **your right to rectification.** To request that we correct any errors in your personal data, that we update your personal data as required, and we complete data you think is incomplete.
- **your right to erasure.** To request that we erase your personal data. Data can be erased in limited circumstances, where it is no longer necessary in relation to the purpose(s) for which it was collected or processed.
- **your right to restrict processing.** To request that we restrict the processing of your personal data, in whole or in part, where: (a) the accuracy of the personal data is contested; (b) the processing is unlawful but you object to the erasure of the personal data; (c) we no longer require the personal data for the purposes for which it was collected, but it is required for the establishment, exercise, or defense of a legal claim. We can consider your request unless it is lawful for us to continue processing your data without consent.
- **your right to data portability.** To request that we send your data to you or someone else in a format that is readable in a different system.
- **your right to object.** To request that we do not transfer your personal data to unaffiliated third parties for any purposes or request that we change the way we contact you.
- **your right to obtain a copy of the safeguards** under which your personal data is transferred outside the EEA.
- **your right to lodge a complaint** with your local supervisory authority for data protection.

Before disclosing to you any personal data requested, we may ask you for additional information to confirm your identity and for security purposes. We reserve the right to refuse your request, or charge a fee where permitted by law, for example if your request is manifestly unfounded or excessive.

Our commitment to data security

In order to prevent unauthorized access, maintain data accuracy, and ensure the correct use of information, we have put in place appropriate physical, electronic, and managerial procedures to safeguard and secure the information we collect online.

We ensure that data is secured against unauthorized external and internal access. Data is held securely and access is restricted to named individuals to fulfil a valid business need. Access is revoked once the need is fulfilled.

Data is only extracted to fulfil a business need and for no other purpose. Extracts of data from the database are transferred securely within the Vitaccess network and are destroyed after the task is complete. Data is never shared on physical devices in publicly accessible locations in the Vitaccess network.

All data management activities and controls are documented in the ISO 27001-certified Vitaccess Information Security, Physical and Environmental Security, and Cryptographic Controls policies.

We will attempt to resolve any complaints regarding the use of your personal data in accordance with this policy. For EU member state residents, you also have a right to lodge a complaint with your national data protection supervisory authority at any time. However, we encourage you to contact us first.

How can I get in contact?

If you have any questions about the study, please contact Vitaccess:

Vitaccess Ltd

The Oxford Science Park

Magdalen Centre

Robert Robinson Avenue

Oxford

OX4 4GA

+44 (0) 1865 818 983

MCT8@vitaccess.com

For questions about our use of your data, please contact our Data Protection Officer: dpo@vitaccess.com.

If you have questions about your rights, or to use them, contact Egetis Therapeutics:

Egetis Therapeutics AB

Klara Norra Kyrkogata 26

SE 111 22 Stockholm

Sweden

+46 (0) 86 797 210

privacy@egetis.com

How can I make a complaint?

You can complain to the UK Information Commissioner's Office if you are unhappy with how we have used your data:

Information Commissioner's Office

Wycliffe House

Water Lane

Wilmslow

Cheshire

SK9 5AF

+44 (0) 303 123 1113

<http://ico.org.uk/make-a-complaint/>

Changes to this policy

We may update this policy from time to time, and we will make any new versions available on the survey website. This policy was last updated on 28 March 2022.

