

Privacy Policy

Last Updated: 5/24/2022

RTI International (RTI) takes your privacy seriously and is committed to protecting your Personal Information. This Privacy Policy ("Policy") sets out the ways in which Personal Information provided to us by you is used, disclosed, and kept secure by RTI. This policy applies whenever and wherever we collect your Personal Information through our relationship with you. This includes when you use the mapMECFS website ("site"), electronic services, or other digital platforms, so please read this Policy carefully. By continuing to use this site, you agree to the terms of this Policy. If you do not agree with the terms of this Policy, please do not provide us with your Personal Information or interact with this site. If you have already created an account, you may contact us at mapmecfs@rti.org to remove your information.

About RTI

RTI is an independent, non-profit research institute dedicated to improving the human condition. We combine scientific rigor and technical expertise in social and laboratory sciences, engineering, and international development to deliver solutions to the critical needs of clients worldwide. This Policy applies to all companies owned by RTI.

About this Policy

This Policy explains what Personal Information we collect about you, how we may use it, when we may disclose the information, and the steps we take to ensure that your Personal Information is kept secure. We also explain your rights with respect to your Personal Information.

Please note that the site may contain links to third-party websites/digital platforms that are provided for your convenience. RTI is only responsible for the privacy practices and security of our own digital platforms. We recommend that you check the privacy and security policies and procedures of each website/digital platform that you visit.

How to contact us about your Personal Information or this Policy

If you have any questions about this Policy or about how your Personal Information is used, disclosed, or secured by RTI, please email us at mapmecfs@rti.org or write to us at the following address:

Global Privacy Officer
RTI International

P.O. Box 12194
Research Triangle Park, NC 27709

How we use and collect your Personal Information

Your Personal Information may be collected when you access or use this site, open or respond to our emails, enter your information into a form on this site and submit that form, visit any page online that displays our content, and link to the site via a social networking site.

RTI defines “Personal Information” as any information that identifies you either directly (such as name, address, email address, telephone number, internet protocol (IP) address, or geolocation) or indirectly (such as gender, race, ethnicity, or location) that, when combined, may identify you. We may also infer your country of location from the IP address you have used to access our digital platforms.

All Personal Information that we collect about you will be recorded, used, and protected by us in accordance with applicable data protection legislation and this Policy. We may supplement the Personal Information that you provide with information that we obtain from other sources.

This site will collect the following Personal Information from you:

- Required: Username, full name, email, password, institution, internet protocol (IP) address
- If provided: Address and phone number
- Any additional information provided in the prompts “Please provide a 2-3 sentence summary explaining how you intend to use the data on the site” and “Describe your ME/CFS-related research goals and provide links to your relevant publications, laboratory website, online bibliography, or a link to your sponsor (PI).”

We use your Personal Information to:

- Determine user account eligibility by sharing this information with the National Institutes of Health;
- Operate, maintain, and improve the site;
- Assess Internet activity, such as your browsing activity on the site, IP address, cookies, and geolocation data;

- Track, manage and audit data access and use in compliance with data use agreements or agreed upon terms of use (only when logged on to specific areas of the site);
- Contact you if we suspect there has been an unintended use or disclosure of personal information, a use of data that you provided to this site that violates agreed upon terms, or that data you downloaded was shared in violation of agreement terms;
- Provide information to you about the site including, but not limited to, site updates, new features, upcoming site-relevant events or proceedings, and to answer direct or indirect questions about the site; and
- Perform analytics including the use of third-party vendors and conduct client research.

Other site users will also have access to Personal Information that you share to and within the website, such as your username, institution, and email address.

Collection of Data from Outside the United States

Please note that RTI is headquartered in the United States of America. If you are outside the United States and provide your data to RTI, we will take proper steps to ensure that your information is protected in accordance with this Policy.

In addition, RTI recognizes that the European Union (“EU”) has established a data protection policy effective May 25th, 2018 known as General Data Protection Regulation (“GDPR”). This regulation applies to countries within the EU and governs the transfer of data outside of the EU. GDPR restricts companies in the EU from transferring personal data about individuals to the United States unless there is “adequate protection” for such personal data when it is received in the United States.

Transfers of data can also occur when RTI has your consent or the transfer is necessary for RTI to perform requirements under a contract that you have entered into with RTI or secure your information. RTI has implemented appropriate administrative, technical and organizational measures so that the use of your Personal Information meets the requirements of the GDPR. Under GDPR, individuals located in the EU/EEA are allowed the following protections with respect to your Personal Data:

The right to access – You have the right to request that RTI provide copies of your personal data. We may charge you a small fee for this service.

The right to rectification – You have the right to request that RTI correct any information you believe is inaccurate and complete any information you believe is incomplete.

The right to erasure – You have the right to request that RTI erase your personal data, under certain conditions.

The right to restrict processing – You have the right to request that RTI restrict the processing of your personal data, under certain conditions.

The right to object to processing – You have the right to object to RTI's processing of your personal data, under certain conditions.

The right to data portability – You have the right to request that RTI transfer the data that we have collected to another organization or directly to you, under certain conditions.

If you make a request, we have one month to respond to you. If you would like to exercise any of these rights, please contact RTI at our email: mapmecfs@rti.org

Or write to us at:

Global Privacy Officer
RTI International
P.O. Box 12194
Research Triangle Park, NC 27709

If you reside in Canada, you may have the right to be provided with access to Personal Information that we have about you and written information about our policies and practices with respect to the transfer of your Personal Information to vendors outside Canada. To find out more, please email us at listen@rti.org.

Pursuant to Section 1798.83 of the California Civil Code, residents of California can obtain certain information about the types of Personal Information that companies with whom they have an established business relationship have shared with third parties for direct marketing purposes during the preceding calendar year. The law provides that companies must inform consumers about the categories of Personal Information that have been shared with third parties, the names and addresses of those third parties, and examples of the types of services or products marketed by those third parties. To request a copy of the information disclosure provided by RTI pursuant to Section 1798.83 of the California Civil Code, please contact us at listen@rti.org or the address stated above. Please allow thirty (30) days for a response.

In all instances where we disclose your information to third parties, we will ensure that your information is appropriately protected.

Notification of a Disclosure of Your Information

Cookies

Similar to many other website operators, we use standard technology called “cookies” on our site. Cookies are small pieces of information that are stored by your browser on your computer's hard drive and are used to record how you navigate this site on each visit. We use a service provider, Google Analytics, to perform analytics services.

Security of information

We take the security of your Personal Information seriously and use commercially reasonable security procedures to protect Personal Information you provide to RTI. When you submit your information to us, we use industry standard Secure Sockets Layer (SSL) encryption technology to guard your information.

In addition, we have security procedures in place to protect our paper-based systems and computerized databases from loss and misuse. We only allow access to them when it is necessary to do so, and then under strict guidelines as to how the Personal Information may be used.

Where a password is required to access certain areas of our digital platforms, you are responsible for keeping your password secure and confidential. Please do not share or disclose your password to any other person.

While RTI believes these security measures to be adequate, no method of transmission over the Internet or method of storage is completely secure. Please know that while we will make every effort keep your information secure, there is still a risk that your Personal Information could be misappropriated, and we cannot guarantee its absolute security.

Monitoring/Analytics

We use Google Analytics to perform analytics services. Google is a member of the Digital Advertising Alliance (“DAA”). You may wish to visit optout.aboutads.info, which provides information regarding targeted advertising and offers an opt-out for DAA-participating companies.

Children’s Online Privacy

RTI does not collect data from children and does not intend that any portion of the site will be accessed or used by children under the age of thirteen (13), and such use is prohibited. This site is designed and intended for use by adults. By using the sites covered by this Policy, you represent that you are at least eighteen (18) years old.

More about your information—your rights

You may correct or update your Personal Information at any time by emailing us at mapmecfs@rti.org. Please include your name, username, institution, and email address when you contact us, as this helps us ensure that we accept amendments only from the correct person. We encourage you to promptly update your Personal Information if it changes.

We will securely retain your information for as long as is reasonably necessary and in accordance with applicable law. If you wish to submit a request that your data be deleted, please email us at mapmecfs@rti.org. You have the right to receive a copy of the Personal Information that we hold about you. Please write to us at the email address above if you wish to exercise this right.

Changes to this Policy

We aim to meet high standards, so our policies and procedures are constantly under review. From time to time, we may change this Privacy Policy. Accordingly, we recommend that you check this page periodically to review the latest version.

Where to make a complaint

If you have a complaint regarding any aspect of your Personal Information or this Policy, please write or email us at the above addresses. For individuals located in the European Union, you may contact the appointed Data Protection Authority (DPA) for your country.