

mapMECFS DATA USE AGREEMENT

I request access to data provided by mapMECFS for the purpose of scientific investigation or the planning of clinical research studies and agree to the following terms.

1. I will receive access to de-identified data and will not attempt to establish the identity of any of the ME/CFS research participants from this data including myself. Furthermore, I will not attempt to contact any research participants, their physicians, or their family members.
2. I will not attempt to make direct contact with ME/CFS investigators or staff at sites concerning additional information regarding individual participants.
3. I will not further disclose these data beyond the uses outlined in this agreement and my data use application and understand that redistribution of data in any manner is prohibited.
4. I will not share data with anyone on my team, at my institution, unless they have registered with mapMECFS and, by doing so, agreed to this agreement.
5. I will respond promptly and accurately to requests to update information regarding the unpublished results and publications arising from use of this data.
6. I will comply with applicable rules and regulations, including those that might be imposed by my institution and its institutional review board, in requesting these data.
7. I will make only lawful use of the data, and will only use it in compliance with all applicable federal, state, and local laws and regulations, and with this agreement. I will not use the data in any way to violate someone's rights, including copyright, trademark, trade secret, right of privacy, right of publicity or other rights.
8. I understand that data that I download is offered "as is", and that no representations or warranties on the accuracy or completeness of the data are made.
9. If I publish abstracts using data provided under this agreement, I will cite the original data and funding sources in the abstract as space allows.
10. If I publish manuscripts using data provided under this agreement, I will cite the original data source and, if available, the corresponding publication. I agree to add mapMECFS to the Acknowledgements section.
11. I will utilize administrative, physical and technical safeguards similar to those used for other data in my organization to prevent unintentional disclosure or use of the data other than as provided for by this agreement.
12. I will report any use or disclosure of the data not provided for by this agreement of which I become aware to mapmecfs@rti.org within five (5) days of becoming aware of such use or disclosure.
13. All public announcements of research to be done with this data (e.g., press releases, social media discussions) will acknowledge the original data source and, if available, the corresponding publication, and mapMECFS, as is appropriate.
14. I understand that any processed data that I download might be preliminary and that results may change as new methods of analysis are implemented.
15. If I download data for the purposes of analysis and future publication in the form of abstracts and/or publications, I will note any defined version of the data I download, and I will do due diligence to check the database to determine if updated data has been provided prior to submission of any material for publication.
16. I agree that no data or analyses will be used for human diagnostic purposes, for informing treatment decisions, or for other clinical or medical purposes.

If I upload data to mapMECFS for the purpose of enabling access to it for scientific investigation, teaching or the planning of clinical research studies, then I agree to the following terms.

1. I have all necessary rights in the data to provide it for upload, and I am authorized by the institution with which I am affiliated and/or employed to upload the data and accept these terms.

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2. I make no representations with respect to the accuracy or completeness of the uploaded data, and the data is offered "as is". If errors with the provided data are identified at a later date, I agree to update the uploaded for accuracy.
3. Nothing that I upload, post, transmit, distribute, or otherwise publish will contain a software virus or other harmful component to the best of my knowledge.
4. The data that I upload may be shared on mapMECFS with anyone who has agreed to the terms above for downloading the data, provided, however, that I or the institution with which I am affiliated and/or employed retains the ownership of the data. I acknowledge that Research Triangle Institute employees or contractors will be able to see and use the data for the purposes of administering the site and the data repository.
5. The data will not contain protected health information or "PHI" under HIPAA or identifiable personal information or "IPI" under the Common Rule (45 CFR 46), as may be updated from time to time. Data that could be used to identify a single individual will either be suppressed or included in mapMECFS as grouped data.