

Solve M.E. Answers Reader Questions

Q: *I want to join the You+ME Registry but I'm concerned about the privacy of my data. Is the Registry secure?*

A: Yes! We take privacy seriously and follow strict security protocols and processes to protect participant information. We will never sell, rent or lease any information about you.

Participant data is encrypted and stored in a secure database managed by Solve M.E. research staff who are certified in Human Subjects Research and our partners.

Personal identifiers, including your name and anything else that can be used to easily identify you, are removed from the dataset, and the "anonymized" health information is made available on a secure platform for research. We require investigators seeking access to



anonymized data in You + ME to submit an application to Solve M.E. and the You + ME Innovation Council, a group of patient, research, and data experts. We track the activity of researchers who use the platform.

Biosamples are only collected with additional consent from participants. The biosamples are labeled with a coded number to protect their privacy and confidentiality. The use of biosamples by researchers includes an additional level of approval and vetting.

Q: *Are we able to download/export our tracking data from the You + ME app so it can be shared with our doctors? Many patients would significantly benefit from the ability to share this data with their physicians. It would document the significant downward spiral of the ability to function in even basic daily activities that comes with PEM (Post-Exertional Malaise).*

A: The You + ME tracking app allows you to record symptoms, life events, and activity on an ongoing basis. This "moving picture" provides researchers with more detailed information on how your health changes over time. But it was also important to create a way for people to get insight into their own illness and provide tools to communicate the day-to-day impact with loved ones or a healthcare team.

While the app does not currently have an export data feature, this is a priority for development! We're currently working with community members on the best way to bring



this feature to the app and it should be ready soon.

In the meantime, you can use the app's "Insights" screen to pick up to 5 symptoms to graph over a custom date range. You can also view select self-reported life events and your general wellness score over the same time period.

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