



SOLVE M.E.

RESEARCH 1st

You + M.E. Registry **TAKEOVER EDITION** SPRING 2020

Your Guide to the You + M.E. Registry

Across the world, people and governments are settling into a life that none of us were prepared for. For the first time, the global community is learning what life within four walls feels like—a reality that those living with ME/CFS know all too well.

Since its earliest recorded diagnosis in the 19th century as 'neurasthenia', ME/CFS has known many names. Once mistaken for other conditions, it is thanks to the resilience and perseverance of the ME/CFS community that the first formal case definition for ME was proposed in 1988 by Dr. Melvin Ramsay, who correctly understood the condition to be physical—not psychological—in nature.

Since that time, researchers studying the condition have gathered increasingly clear evidence that ME/CFS develops and is sustained by underlying biological mechanisms. Medical professionals around the world have described disease presentations, clinical features, and abnormalities across body systems in patients. Their work demonstrates that ME/CFS strikes people from every age, racial, ethnic, and socioeconomic background.

However, despite decades of research, the root cause of this condition is still not fully understood. There is no diagnostic test, no FDA-approved treatment, and no cure.

Key questions remain: Why is there such a broad range of symptoms? Is this a single disease or a cluster of conditions? Why is it that some people respond to treatments and others do not?

You + M.E.—an ME/CFS registry and biobank—aims to capture insights from tens of thousands of community members like YOU, paving the way for a global big data movement in ME/CFS.

YOU

The people who know the most about their illness are the people who are living with it every day. You have a unique expertise that is invaluable to researchers. Biomedical research is entering a new period fueled by “patient power”. By entering data on your lived health experience, including symptoms, quality of life, and treatment outcomes, you are contributing to a data repository that will be invaluable to researchers.

To answer our most pressing questions about ME/CFS, the scientific community must do what ME/CFS patients have been asking for all along : listen. By tapping into the wealth of knowledge provided by people living with ME/CFS, we can use a big data approach to aggregate individual experiences into community-level patterns that can help researchers better understand the disease course, find and validate subgroups, initiate studies into disease mechanisms and treatments – and then quickly translate those discoveries into clinical care.

Rachael Carder, a person with ME/CFS

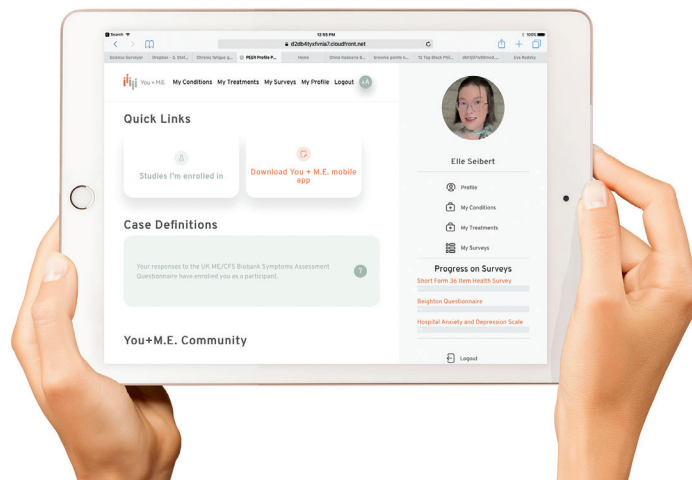
“Health tracking just might help individuals to understand their health at a deeper level and to make more informed decisions, and can offer us a chance to come together as a community and support each other. Now I want to zoom out and imagine the research insight that we as a community could get when researchers have a chance to work with this data.”



Visit the You + M.E. blog page at youandmeregistry.com to read more about Rachael's perspectives on the Registry.

YOU + M.E.

You + M.E. collects health information from people living with ME/CFS and controls. The registry platform includes a web-based User Portal that allows for easy data entry, while protecting participant privacy. After a person with ME/CFS or someone without the disease (a control) registers on the website, they can complete surveys that capture their health history, quality of life, other diagnoses, treatments and outcomes. And because it's important to track symptoms as they fluctuate over time, we've also built a mobile app to track symptoms, life events and activity levels (you can learn more about that on page 3).



YOU + YOUR DATA

We encrypt all participant data and store it in a secure database managed by Solve M.E. research staff who are certified in Human Subjects Research. Personal identifiers (i.e. names and other identifying information) are removed and the “de-identified” health information is made available on a secure platform for research. Researchers who want to analyze the Registry data are vetted by the You + M.E. Innovation Council, a group of ME/CFS, research, and data experts. **We will never sell, rent, or lease any information you provide us.**

Alongside your health data, biological samples are critical for biomedical research. So, You + M.E. is building a repository of samples from people with ME/CFS and controls. We are planning for a collection process that will allow a large number of people to participate, even from home – more on this soon!



1. PEOPLE

Anyone with ME/CFS and healthy controls can sign up



2. REGISTRY

Everyone enters self-report baseline information into a secure web portal



3. APP

Participants with ME/CFS get a link to download the You + ME mobile app



4. TRACKING

Symptoms, life events, activity levels, and overall wellness are tracked over time in the app



5. BIOBANK

People with confirmed ME/CFS and healthy controls provide blood samples



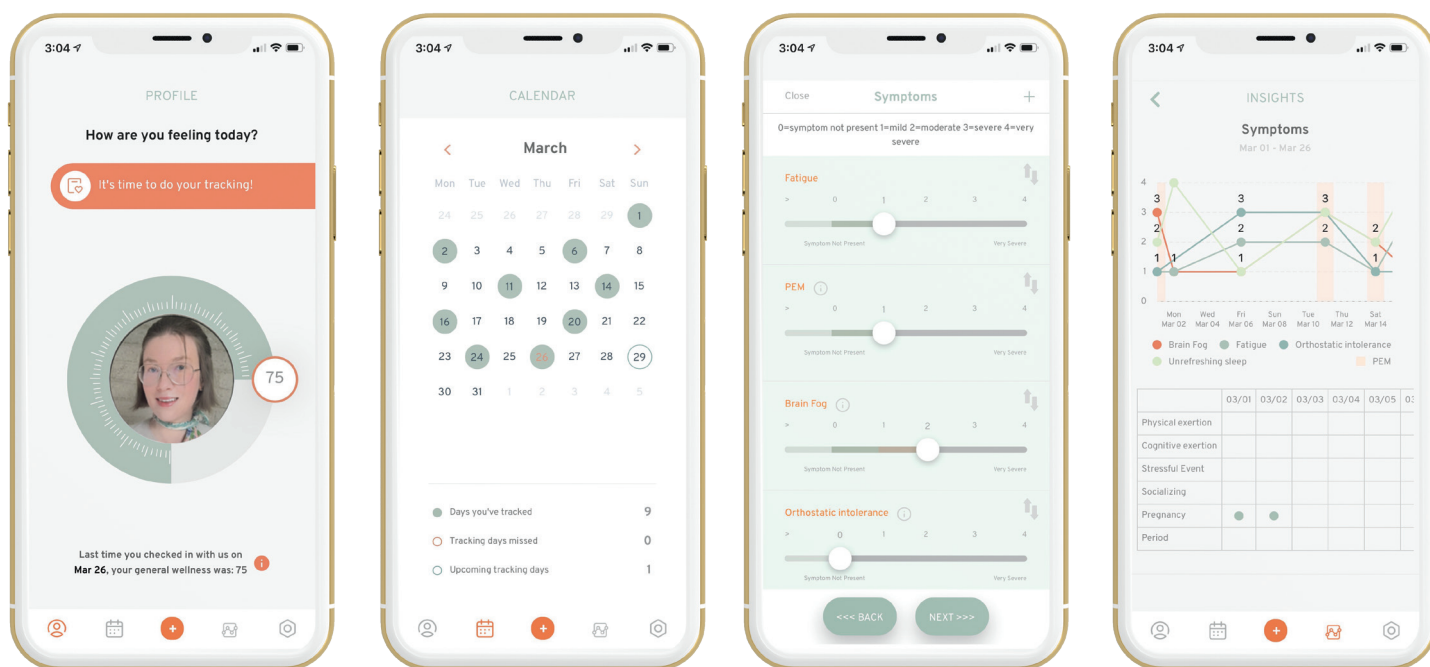
6. RESEARCH

Researchers vetted by a review panel can access de-identified data and apply for biosamples

YOU + YOUR TRACKING APP

Once you complete the baseline data capture via the User Portal, you will be given the option to download the ‘You + M.E. Tracking App’. The Tracking App is designed to track your symptoms, life events, activity levels, and general wellness over time. The data collected via the app will be added to the data you enter in the user portal to create a robust picture of your health.

You can learn more about how to use the app by watching our walkthrough video at youandmeregistry.com.



THE PROFILE TAB

Welcome to the Profile Tab! This is the central hub of the Tracking App. Here, you can see a snapshot of your self-reported wellness score, a general measure of health. Through this screen, you have the option to start tracking your symptoms for the day.

THE CALENDAR TAB

On this screen, you can see your tracking days for the month. The first time you sign on, you will be given the choice to receive push notifications on a regular schedule every day, every 2 days, every 3 days, or simply once a week. As you settle into a routine, you always have the option to track more or less days, depending on what works best for you.

THE SYMPTOMS TAB

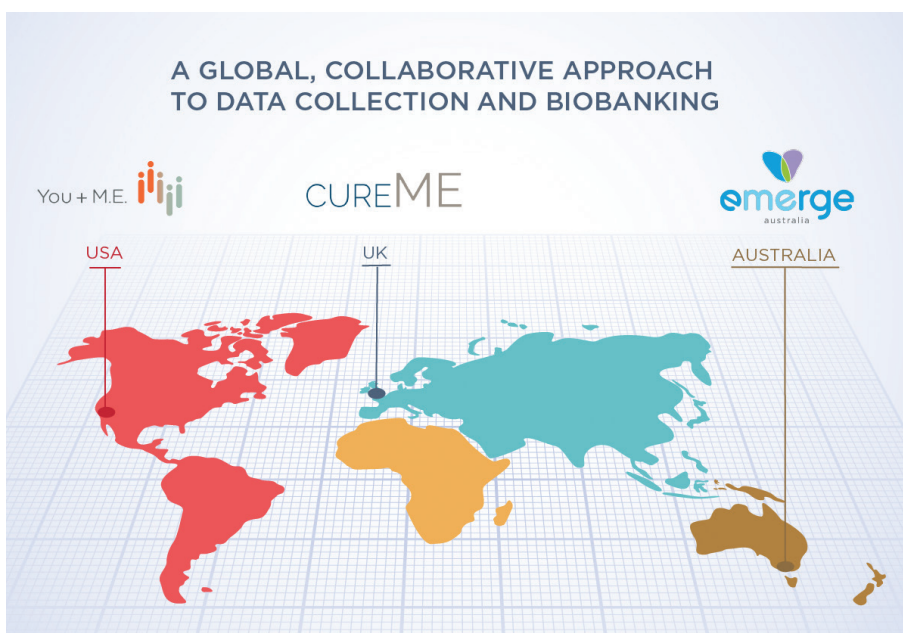
This is where you capture data on the You + M.E. Core Symptoms: fatigue, brain fog, post-exertional malaise, orthostatic intolerance and unrefreshing sleep. Because we know there is a wide array of symptoms associated with the condition, we also invite you to personalize this screen by selecting additional symptoms from an extensive list we've developed based on feedback from the community!

THE INSIGHTS TAB

At long last, we arrive at the Insights Tab! This is where your data comes alive. In this tab, you have the ability to graph your symptoms over time, and see how your day to day activities have impacted them.

US

The You + M.E. Registry also includes a researcher web portal for researchers to access data, identify potential research participants, and request biosamples. Researchers who want to use the data, the samples, or both, will submit an application to Solve M.E. and the You + M.E. Innovation Council. The Innovation Council is a key part of the You + M.E. Community. This group will not only review proposals for data and biospecimen use but will also generate creative ideas for use of the data and innovative approaches to recruit and retain participants. The Innovation Council is made up of those with ME/CFS, care partners, clinicians, researchers, epidemiologists, as well as those with AI/machine learning expertise and experience with big data. Researchers who use the data will be required to share their methods and findings with the global community.



US + THE WORLD

When we work together, nothing is impossible. You + M.E. is a resource the global ME/CFS community can benefit from! Together with our collaborators at CureME and Emerge Australia, we aim to bring the power of big data to ME/CFS. By joining forces and consolidating our respective data sets, we are working to overcome data siloes to develop a global, unified approach to ME research.

US VS. COVID-19

People living with ME/CFS commonly report that an infection preceded their chronic illness. As a number of viruses, including previous coronavirus strains, have been implicated as triggers of ME/CFS, we took great care in optimizing the You + M.E. Registry to track both the impact of COVID-19 on people with ME/CFS and the development of ME/CFS-like symptoms following COVID-19 exposure.

As part of our team's response to COVID-19, we've integrated a COVID-19 questionnaire in the You + M.E. survey dashboard so that we can track the impact of COVID-19 on the health of people with pre-existing ME/CFS. We are also partnering with existing COVID-19 registries and apps to facilitate follow-up and referral to You + M.E. should people find themselves experiencing post-viral symptoms. While many research projects have come to a stop due to stay-at-home orders and lab closures, You + M.E. is completely online, aggregating each individual's story and data into a global dataset from the safety + comfort of home.

STAY IN TOUCH!

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You + M.E. Registry and Biobank:
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