

You + M.E.: Bringing the Big Data Revolution to ME/CFS

By Sadie Whittaker, PhD, Chief Scientific Officer, Solve M.E.

The development of the You + M.E. Registry and Bio-bank has been a labor of love (and at times frustration!) for nearly two years now. When I stepped into the CSO role at Solve M.E., one of my first priorities was to redesign the existing registry and biobank. Our vision: to create the largest possible global data set from people living with ME/CFS and healthy controls. I have spent much of my career working in oncology and have witnessed firsthand the impact that Big Data has had in advancing our understanding of what was once a poorly understood illness. Data has allowed us to understand that cancer isn't a single disease, but rather a myriad of diseases, each with an individual etiology that can be targeted with a different treatment.



I firmly believe that a global registry and bio-bank will be the single most impactful driver of progress in ME/CFS, deepening our understanding,

helping us pick apart the heterogeneity, and driving us towards treatments. I believe it will help us answer some fundamental questions that we've all circling around: why do some people respond to some treatments and others do not? Why can some people return to a higher level of functioning while others remain house or bed-bound? Is this a single disease or is it a cluster of different diseases?

But first, we had to create it! We started out by establishing some guiding principles. As big believers in the principles of human-centered design, we knew we wanted to partner with the community to identify what data we should collect, how often, and by what mechanism. We knew we wanted to leverage advances in digital health technology to integrate the ability to track symptoms on an ongoing basis via an app, but what should that look like? The community of patients, care

partners, researchers, and clinicians were invaluable partners in designing all aspects of You + M.E., generously sharing their experiences, their time, and their creative thinking.

Collaboration with others collecting data was also central to our process. Rather than a number of separate silos of data around the world, what if we could create a single Global Data Repository? (It's harder than it sounds!) Together with our lovely partners at **CURE ME** in London we co-created a data capture process that will facilitate data sharing and cooperation between our two registries. Our partnership with **EMERGE** around the creation of an Australian Registry is just beginning, and we are starting to map out how we will collaborate.

None of this would have been possible without our partners at **NIH NINDS**, Vicky Whittemore and Andrew Breeden, who have provided both intellectual and financial support to help us create You + M.E. And I would be remiss not to mention Allison Ramiller, Solve M.E.'s Director of Research, who has been the driving force behind the creation of You + M.E., and for whose determined efforts I am eternally grateful.

Last, many of you have asked about the name: You + M.E. represents the community we hope to build. It represents You + Your Disease; You + Your Healthy Control; You + the hundreds of thousands of others who will contribute their data; You + the network of researchers who will use the data to better characterize this illness. Working together we can revolutionize understanding of ME/CFS. ■

Join the You + M.E. community. Learn more at our website <https://youandmeregistry.com/> and sign up to join us. I would also encourage you to check out our ME Impact Tool <https://youandmeregistry.com/m-e-impact-tool/>. It was designed to communicate a visual gut punch of how debilitating ME/CFS is. Whether it be debilitating symptoms or disengaging from life activities to avoid a crash, ME/CFS crowds everything else out.