



“Behind every datapoint, there’s a person, a story, and a chance for a better tomorrow”

Introducing the AusME Registry and Biobank

The 'AusME' initiative reflects Emerge Australia's dedication to ensuring that the voices of those with lived experience, play a crucial role in the co-design of ME/CFS and long COVID research in Australia. As Custodians of the AusME Registry and Biobank, Emerge Australia considers it essential to support Australian research and researchers in accelerating meaningful outcomes for those living with ME/CFS and long COVID, ultimately leading to an improved quality of life.

The Mason Foundation/Equity Trustees have supported Emerge Australia's Custodianship since 2019. Their renewed support sees the original ME/CFS registry expanded and rebranded as the *Australian ME/CFS and long COVID (AusME) Registry and Biobank*.

The AusME Registry and Biobank seek participation from individuals 12+ years who:

- Live with ME/CFS and/or long COVID
- Are supporters/healthy volunteers

Community members can sign up as AusME participants at www.ausmeregistry.org.au. After consenting, participants complete questionnaires about their health, medical history, and demographics. These surveys are designed to be completed with the participants' comfort in mind, allowing them to be filled out over multiple sessions within their energy limits. Participants are also informed about ME/CFS and long COVID studies in Australia and can opt to become blood donors for the AusME Biobank.

The AusME Registry and Biobank have ethics approval from La Trobe University's Human Research Ethics Committee (project #HEC20161 and #HEC20027).

Collaborate with Emerge Australia to advance ME/CFS and long COVID research

Emerge Australia is dedicated to supporting Australian researchers who are working to uncover the causes and develop effective treatments and diagnostic tests for ME/CFS and long COVID. The inclusion of the AusME Registry and Biobank through the co-design of new research projects will help to clarify the effects and consequences of these conditions on those affected.

Approved researchers can access data and biosamples through Emerge Australia's Medical and Scientific Advisory Committee (MSAC). The MSAC comprises a dedicated team of clinicians, researchers, and representatives of those with lived experience of ME/CFS and/or long COVID. MSAC meetings occur bi-monthly throughout the year. All studies using human data or biosamples must have ethical approval from an NHMRC-approved Human Ethics Committee.

What partnership/collaboration with Emerge Australia could mean for your research study:

- Co-design of research study, grant applications and support letters
- Study advertising and participant recruitment
- Access to AusME Registry and Biobank data and biosamples

For further information and assistance, contact Emerge Australia's Research Manager, Dr. Michelle Tavoletti at michelle.tavoletti@emerge.org.au or on 1800 865 324.