



## Can We Reach Consensus on a Research Case Definition for ME/CFS?

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| <b>Grant Amount</b>      | £11,178.20  |
| <b>Location</b>          | DePaul University, USA  |
| <b>Research Field</b>    | Infrastructure  |
| <b>Lead Researcher/s</b> | Professor Leonard Jason   |
| <b>Start Date</b>        | 15/09/2023  |
| <b>Duration</b>          | 12 months   |
| <b>Status</b>            | In progress   |
| <b>Latest Update</b>     | <a href="https://meassociation.org.uk/2025/09/research-new-study-to-harmonise-research-definitions-in-me-cfs/">https://meassociation.org.uk/2025/09/research-new-study-to-harmonise-research-definitions-in-me-cfs/</a> |

### BACKGROUND

Inconsistent diagnostic criteria have long undermined the quality and comparability of ME/CFS research. Studies often include participants who may not meet core ME/CFS definitions, leading to unreliable findings and fragmented evidence. To address this, the me association launched the *research case definition consensus statement*, which has already gained international support from researchers, clinicians, and advocacy groups.

Building on this momentum, this dedicated funded study will develop a consensus-informed research case definition—one that reflects the lived experience of patients and the clinical expertise of ME/CFS specialists.

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### PROJECT DETAILS

This project will:

- **Survey** people with ME/CFS, patient representatives, clinicians, and researchers to identify essential symptoms for a research case definition
- **Conduct a scoping review** of severity measures to ensure consistent evaluation of symptom intensity
- **Host a panel discussion** at the 2025 IACFS/ME conference to explore controversies and build consensus

The project will produce:

- A consensus-informed framework for ME/CFS research definitions
- A published report
- Practical guidance for researchers worldwide

This work will clarify inclusion and exclusion criteria and standardise symptom assessment—strengthening the validity and reliability of future ME/CFS studies.

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### IMPORTANCE OF FUNDING

- **Addresses a foundational barrier:** without a consistent case definition, ME/CFS research remains fragmented and difficult to interpret.
- **Improves scientific rigour:** standardised criteria will enhance cross-study comparability and reproducibility.
- **Amplifies patient voice:** co-production ensures that lived experience informs research design.
- **Supports global collaboration:** outputs will guide researchers internationally, fostering alignment across studies.
- **Lays groundwork for better outcomes:** reliable research definitions are essential for developing diagnostics, treatments, and clinical guidelines.