



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

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Location	DePaul University, USA
Research Field	Infrastructure
Lead Researcher/s	Professor Leonard Jason
Start Date	15/09/2025
Duration	24 months
Status	In progress
Latest Update	Update: Can We Reach Consensus on ME/CFS Research Criteria?

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.

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.