

# CAN WE REACH CONSENSUS ON A RESEARCH CASE DEFINITION FOR ME/CFS?

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## BACKGROUND:

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome is a poorly understood and debilitating condition associated with a wide range of symptoms (e.g., extreme fatigue, muscle and joint pain, cognitive impairment, post-exertional malaise (PEM) etc.). Without a diagnostic test available, receiving a diagnosis of ME/CFS is very difficult. Unfortunately, this has led to further dismissal by healthcare providers and members of the community (Friedman, 2019).

Since 1985, 25 case definitions for ME/CFS have been created (Lim & Son, 2020). This complicates diagnosis and forces many people to suffer through this condition alone.

A lack of consensus by clinicians, researchers, government agencies, and patients with ME/CFS has proven to hinder cross-comparability between studies, along with major findings like biomarkers for this condition. This survey aimed to identify areas of contention and agreement within the broader ME/CFS community to inform future directions in this area.

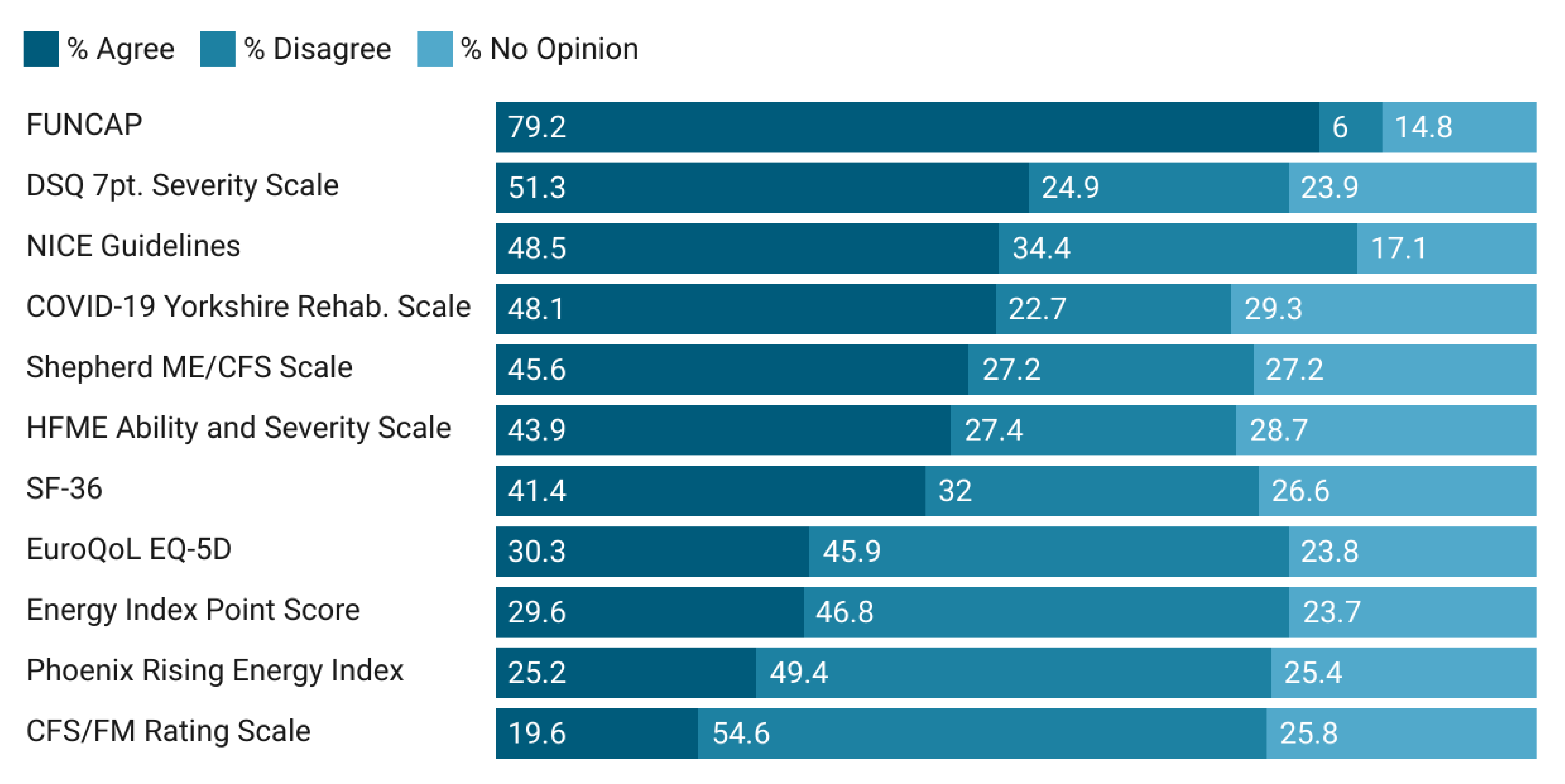
## METHODS:

Survey questions were created using participant feedback from a previous questionnaire (Rathmann et al., 2024). Invitations to complete the survey were distributed via social media and relevant patient organizations.

n = 4,224 participants took part in the questionnaire anonymously. Data was collected via REDCap, an online electronic data capture tool hosted by DePaul University.



“I have had this for 63 years. Most of what the doctors ask is their idea and does not reflect what the patients feel. Ask us.”



## RESULTS:

Question	% Agree
Detailed Selection Criteria	98
Course of Illness Important	95
PEM Required	92
Disease Duration Important	92
Preference of Homogeneous Groups	90
Pacing on PEM Incorporated	89
Morbid Obesity Non-Exclusionary	88
Onset Type Important	85
Sudden or Gradual Onset Important	85
Categorized by Comorbidities	85
Single Severity Measure Only	85
Categorized by Preceding Infection	83
Identify LC or C-19 in pwME	81
Categorized by Treatment Response	74
Mild as Trivializing	69
Research Criteria Stricter than Clinical	65
No Single Diagnostic Label Necessary	40

\*Items in bold >80% agreement.

## DISCUSSION:

Strong agreement on core issues (>90%)

- The use of detailed selection criteria
- Inclusion of PEM and disease duration
- Consideration of homogeneous subgroups and disease duration

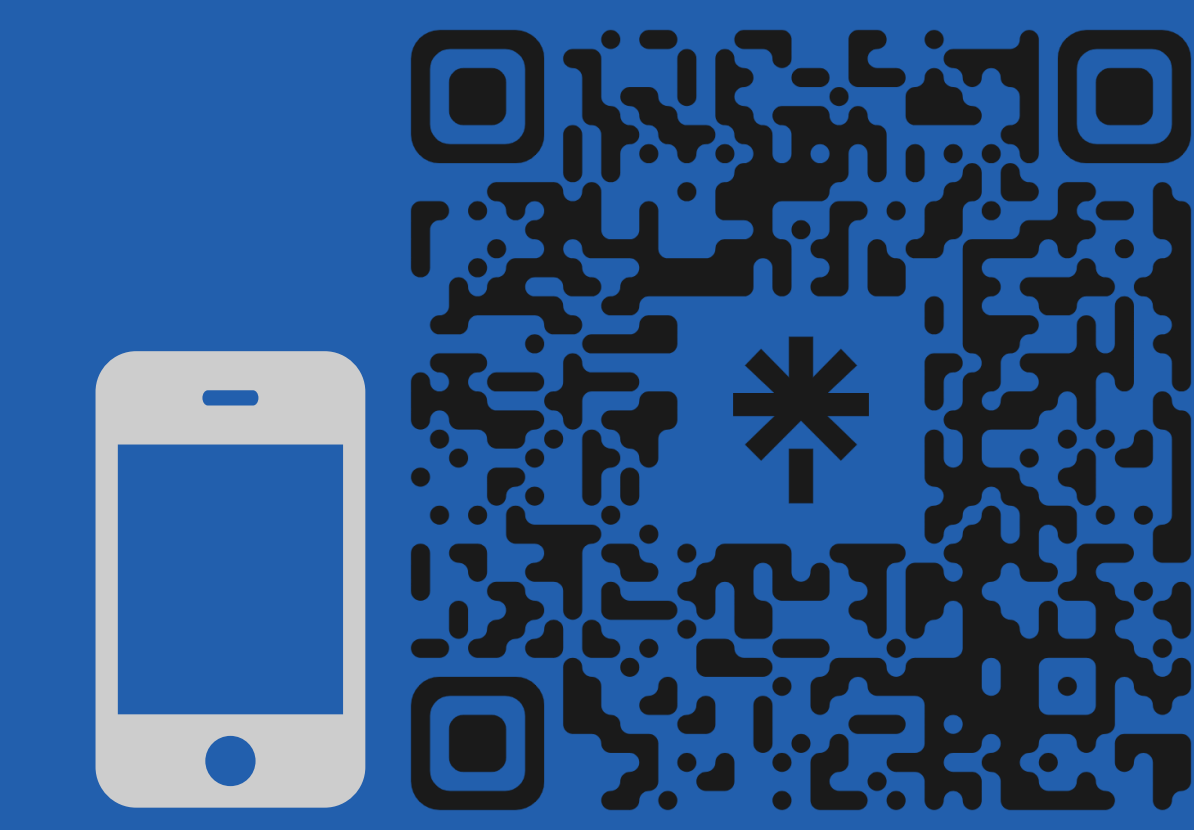
Moderate agreement on (<85%)

- The importance of onset type
- The use of only one severity measure
- Consideration of comorbid conditions and preceding infections
- FUNCAP rated as the most useful measure of illness severity

With approximately 6 in 10 Americans living with a chronic disease (NIHCM, 2025), it is paramount to develop better strategies and management tools to properly care for this growing population in our community.

## ACKNOWLEDGEMENTS:

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