



The ME Association Clinical Assessment Toolkit Phase II: Dissemination and Implementation

Grant Amount	£59,750
Location	University of Manchester
Research Field	Healthcare
Lead Researcher/s	Professor Sarah Tyson
Start Date	01/08/2025
Duration	18 months
Status	In progress

BACKGROUND

A detailed understanding of patients' symptoms and disabilities is central to providing tailored care, but this is a challenge for NHS ME/CFS specialist services because of a lack of accurate, effective measurement tools (known as patient reported outcome measures, PROMs).

Currently, no ME/CFS PROMs could be recommended for clinical use or research because of poor methodological quality. PROMs have much to offer. Research into other conditions shows they can improve understanding of patients' problems, facilitate monitoring, speed up decision-making, and improve communication.

In Phase I of the MEA-CAT project, the research team co-produced (with ME/CFS clinicians and people with lived experience) a series of psychometrically robust PROMs to define the impact of ME/CFS on an individual, their clinical needs, and their satisfaction with the specialist service.

PROJECT DETAILS

Following the success of Phase I, the development of the PROMs, Phase II of this project aims to disseminate and implement them.

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There are three main aims:

1. Dissemination of the development process in peer-reviewed journals.
2. Implementation of the toolkit to make the PROMs readily available to clinicians and people with lived experience.
3. To add three further elements to the toolkit to make it more comprehensive.

The research team will use the same co-production, psychometric and collaborative techniques as Phase I to achieve the following objectives:

1. Dissemination (publications):

Publish papers regarding:

- i. the development and psychometric evaluation of the toolkit assessments,
- ii. ME/CFS symptoms, post-exertional malaise, activity levels, clinical needs, and experience of ME services,
- iii. the impact of ME/CFS on people with severe ME; explore symptom clusters and phenotypes; and compare ME/CFS with Long Covid.

2. Implementation

Having developed the toolkit, it will be made available to as many people as possible by making hard copies available on the MEA website, producing digital versions via two Apps one for individuals to use and one for NHS ME/CFS/LC specialist services.

Completing the toolkit electronically is much quicker, simpler and cheaper than doing it manually as it makes all the calculations and produces the summary reports automatically.

3. Further additions to the toolkit

Three further resources will be co-designed and validated:

- i. a co-morbidities checklist
- ii. a template care and support plan
- iii. and a version of the toolkit for children and young people.

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IMPORTANCE OF FUNDING

Phase II of the project is critical for translating findings from Phase I into impact, it will:

- **Address a critical gap:** There are currently no PROMs for ME/CFS which meet clinical or research standards—MEA-CAT fills this void.
- **Built with rigour and relevance:** Phase I successfully co-produced psychometrically robust tools with patients and clinicians.
- **Improves care and decision-making:** PROMs enhance understanding, monitoring, communication, and service evaluation.
- **Expands the toolkit:** by adding a co-morbidities checklist, introducing a care and support plan template as well as developing a version for children and young people.
- **Strengthens the evidence base:** through the use of peer-reviewed publications, this will expand the evidence base for ME/CFS symptomatology, severities of ME/CFS, symptom clusters, phenotypes... as well as allowing service evaluation.
- **Accessible:** the toolkit will be implemented widely via hard copies and digital apps—making it accessible to individuals and NHS specialist services and enabling automated scoring and reporting.

By funding this phase, this enables the MEA-CAT to move from development to real-world use—empowering patients, improving clinical decision-making, and strengthening the infrastructure for ME/CFS research and care.