



Collaborating with Charities

ELAROS and the ME Association

Development of a digital clinical assessment toolkit and publicly downloadable app to support people with ME/CFS



Background

Myalgic encephalomyelitis / chronic fatigue syndrome is a long-term disabling condition often linked to an infection from which people never fully recover.

The [ME Association](#) has been supporting people with ME/CFS since 1980. This national charity invests in medical research and works to improve health and social care.

This case study focuses on the collaboration between ELAROS and the ME Association which resulted in the development of a digital clinical assessment toolkit and public app to support people with ME/CFS.



Introduction:

ME/CFS is characterised by four key symptoms: debilitating fatigue, unrefreshing and/or disturbed sleep, cognitive/memory problems ('brain fog'), and post-exertional malaise; a worsening of symptoms after activity (of any type) which is often delayed.

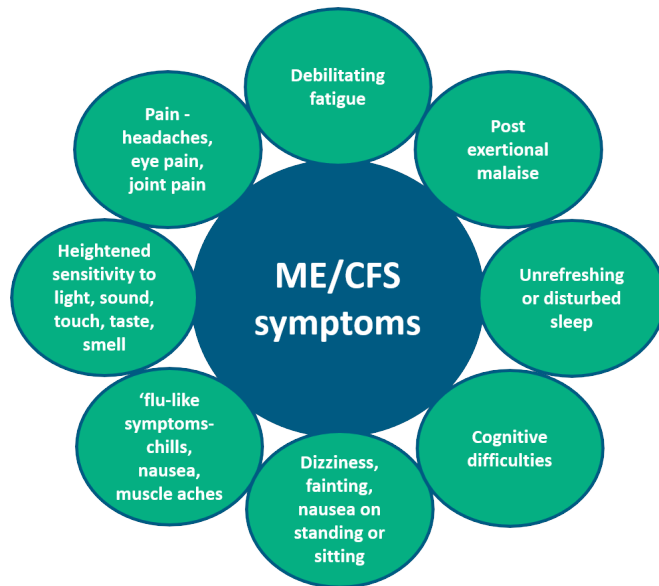
ME/CFS is a complex, chronic medical condition affecting multiple body systems. It affects everyone differently and its impact varies widely - for some people, symptoms cause substantial incapacity.

People with ME/CFS need timely and accurate diagnosis so they get appropriate care for their symptoms, regular monitoring and review, particularly when their symptoms are worsening, changing, or are severe.

Less than a third of people with ME/CFS are able to work, a quarter are severely or very severely affected, leaving them housebound, or even bedbound, and quality of life for people with ME/ CFS is lower than many other disabling chronic conditions. The economic cost of ME/ CFS in the U.K. is estimated to be approximately £3.3 billion/year (1).

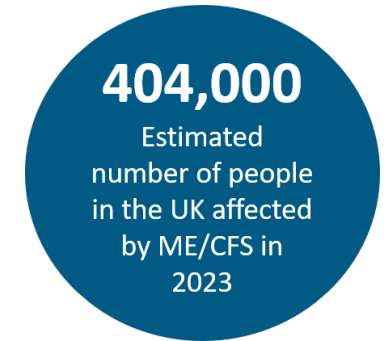
Image source:

ME Association



Data from 2023 estimates that 404,000 people in the UK are affected by ME/CFS.

It is difficult to know the exact numbers as the figures can vary greatly due to lack of specialist services and effective diagnostic methods (2)



The cause of ME/ CFS is unclear, so there is no diagnostic test; diagnosis depends on clinical presentation and assessment of symptoms. Most recent estimates from the DecodeME project suggest it is common, affecting over 404,000 people in the UK which is greater than other common neurological diseases such as MS and Parkinson's Disease.

This project also found promising genetic signals suggesting dysfunction of the immune and nervous systems may be involved. This gives hope that a diagnostic test and effective treatment could follow in the future.

Currently, there is no curative treatment for ME/CFS. Management focuses on pacing to manage energy and activity levels without exacerbating symptoms. Many areas of the country have no NHS ME/CFS specialist services, leaving patients without access to the help they need.

ELAROS' collaboration with the ME Association

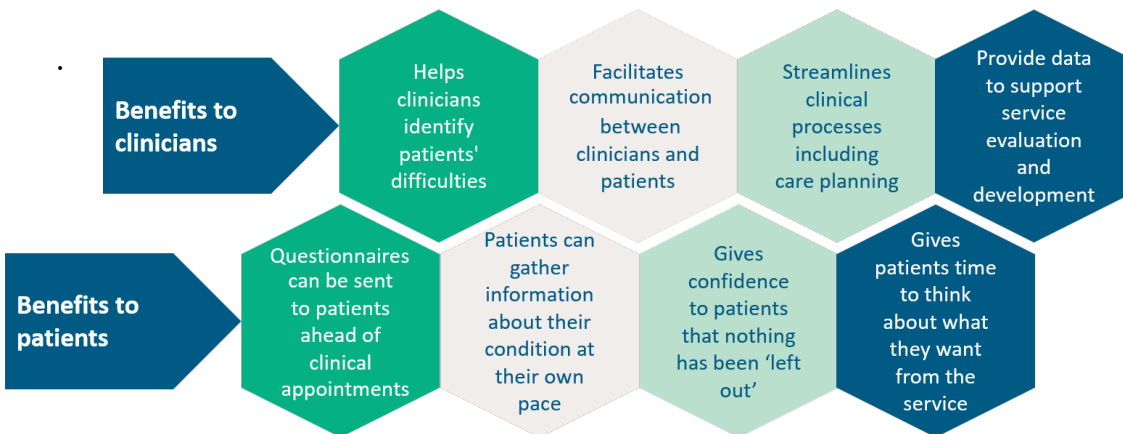
ELAROS, the ME Association (MEA) and the University of Manchester, collaborated on an MEA-funded project to develop a Clinical Assessment Toolkit and a patient app to improve assessment, monitoring and outcomes measures for people with ME/CFS.

Why this project mattered

The NICE Guideline for ME/CFS (3), highlighted the need for effective, consistent assessment and monitoring of people with ME/CFS (PwMECFS) and hence there was an opportunity to create a standardised UK-wide approach to clinical assessment and patient reported outcome measures (PROMs) to overcome challenges in existing services.

The challenges include inconsistent use of PROMs, using generic rather than ME/CFS specific measures, and the use of paper-based questionnaires which are burdensome and with unclear clinical value.

The benefits of the digital toolkit to PwMECFS and Clinicians



Since 2023, the MEA and Professor Sarah Tyson have worked to develop a set of validated clinical measures that assess symptom burden, post-exertional malaise, activity limitations and clinical need.

Most people with ME/CFS utilise NHS specialist services in the early years of their illness when a diagnosis is needed. However, greater numbers of people live without specialist support and it was important that the toolkit was made available to them as well.

The MEA was aware of ELAROS' digital "C19-YRS" platform that was nationally recommended by NHS England and commissioned by NHS Scotland for NHS Long Covid services.

The MEA commissioned ELAROS to develop the digital Clinical Assessment Toolkit to provide the MEA-CAT assessments to NHS ME/CFS specialist services and also to make these available to the public through ELAROS' new app called "Autonom-e", designed to accommodate a range of conditions, which is available to download and try for free from the app store.

The toolkit developed through this project was launched in December 2025 and is available to clinical services through ELAROS' autonom-e platform (4)



Feedback from the ME Association



Professor Sarah Tyson, University of Manchester.

"Working with ELAROS to digitise the ME Association's Clinical Assessment Toolkit has been a very positive experience.

Their expertise in translating clinical ideas into effective digital solutions, and commitment to genuine co-production has been invaluable. By building on ELAROS experience and know-how, we have been able to make the apps available to individuals with ME/CFS and ME/CFS services quickly, effectively and at much lower cost than I had expected"



Russell Fleming, Head of Project Development, ME Association

"The MEA Clinical Assessment Toolkit has been a successful co-production between the MEA, Prof. Tyson (Manchester), Dr Mike Horton (Leeds), clinicians working in NHS specialist services, ELAROS, and most importantly, people with lived experience of ME/CFS.

ELAROS has been an excellent partner in this endeavour and with us every step of the way. They have enabled the toolkit to be accessed and completed digitally, whether by a specialist service utilising the clinical application and licencing arrangement, or by a member of the patient community who might want to monitor progress themselves.

ELAROS are experts at digital integration and their reputation within and outside of the NHS is well deserved. It has been a pleasure to work with them on this project and we look forward to continuing the relationship in the future."

ELAROS and the MEA are partners in University of Leeds' £1.4m NIHR funded HERITAGE project (2026-2028)

This project is cited in the Government's Delivery Plan for ME/CFS. The project will examine the overlap between ME/CFS and Long Covid and explore the cost effectiveness of existing healthcare models for both conditions with the aim of improving quality of care for both.

ELAROS' platform is positioned to support a national service framework within the HERITAGE project and the potential creation of a National Outcomes Database. Additionally, ELAROS will support Imperial College's Rosetta Stone £1.1m project which is funded by the ME Association to investigate shared pathways between ME/CFS and Long Covid with a hope to lead to development of improved treatments.

About ELAROS

ELAROS is a globally connected digital health SME based in Sheffield, UK, that was incorporated in 2010, backed by private investors and with four NHS organisations as shareholders.

ELAROS is a health company rather than a technology company. Its work is collaboration driven and unmet needs led, rather than technology push.

The company is agile, small enough to respond quickly but big enough and connected enough to be able to deliver nationally and internationally.

"Ideas and opportunities come from everywhere and nowhere in particular. It's all about being proactive" Professor Paul O'Brien, CEO ELAROS.

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