Invest in ME Research

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# INVEST IN ME RESEARCH

## Status and Position Update

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## EXECUTIVE SUMMARY

Invest in ME Research (IiMER) is an independent UK charity led by patients and carers with a clear purpose: to accelerate high-quality biomedical research into myalgic encephalomyelitis (ME, sometimes referred to as ME/CFS), improve education and awareness, and advocate for evidence-based policy and healthcare practice. IiMER operates without salaried staff, ensuring that funds raised are directed towards research, collaboration and strategic advocacy.

This update outlines Invest in ME Research's position on the current state of ME research and policy in the UK, identifies persistent barriers to progress, and sets out the actions required to deliver meaningful biomedical and clinical outcomes.

# INVEST IN ME RESEARCH: PURPOSE AND PRIORITIES

## Objectives

The objectives of Invest in ME Research is to energise and facilitate biomedical research into myalgic encephalomyelitis, promote evidence-based education and information, and raise awareness of the profound impact ME has on patients and their families.

## Core principles

Invest in ME Research is guided by the following principles:

- Support research that advances understanding of ME's biological basis, aetiology, pathogenesis and epidemiology.
- Foster collaborations that accelerate scientific discovery, translation and clinical application.
- Prioritise education of policymakers, healthcare professionals, the media and the public to counter misinformation about ME.
- Maintain highly efficient use of funds by operating without salaried staff, ensuring donations directly support research and advocacy.

# RESEARCH LEADERSHIP AND COLLABORATION

Invest in ME Research champions an international, collaborative strategy for biomedical research into ME, recognising that sustained progress depends on coordination rather than isolated initiatives.

Over many years, the charity has been instrumental in establishing and supporting European and international networks, including:

- European ME Alliance (EMEA) – a collaborative body of patient organisations working across Europe.
- European ME Research Group (EMERG) – a network coordinating and accelerating European biomedical research into ME.
- Young European ME Research Group (Young EMERG) – supporting early-career researchers entering the ME research field.
- European ME Clinicians Council (EMECC) – a clinical network promoting shared standards and improved clinical practice.

These frameworks ensure that IiMER-supported research is embedded within wider scientific efforts, enabling cross-disciplinary exchange and efficient use of expertise and resources.

## RESEARCH FUNDING AND PROJECTS

Invest in ME Research funds and facilitates biomedical research primarily within the UK and Europe, with an emphasis on high-quality investigative work with clear translational potential. The charity supports research at established institutions, particularly within the Norwich Research Park, including the Quadram Institute and the University of East Anglia.

A key strategic objective has been the establishment and ongoing consolidation of a UK and European Centre of Excellence for ME — a translational biomedical research hub integrating laboratory discovery with clinical frameworks to accelerate knowledge transfer and improve patient outcomes – in Norwich Research Park where world-class research and facilities exist.

From a policy perspective, government engagement with, and support for this Centre of Excellence would provide strategic stability beyond charitable investment, enable long-term planning, and allow expansion of translational research capacity, including biomarker discovery, mechanistic studies and clinical trial readiness. Such support would also strengthen the United Kingdom’s position within European and international ME research collaboration, aligning with stated objectives on research excellence, innovation and health equity.

## ANNUAL RESEARCH CONFERENCES AND COLLABORATION EVENTS

Since 2006, Invest in ME Research has organised annual international biomedical research conferences and colloquia to:

- Disseminate current scientific knowledge
- Facilitate professional exchange between researchers and clinicians
- Introduce diverse scientific disciplines into ME research
- Engage early-career researchers through targeted initiatives such as Young EMERG workshops

In 2026, the charity will host:

- Young EMERG International Early Career Researcher Workshops
- 15th International Biomedical Research into ME Colloquium (BRMEC15)
- 18th International ME Conference (IIMEC18)

- EMERG26 research collaboration meeting

These events play a critical role in sustaining research capacity and ensuring rapid international knowledge exchange.

## ADVOCACY, EDUCATION AND POLICY ENGAGEMENT

Education and advocacy are central to Invest in ME Research's approach. The charity provides evidence-based information to policymakers, clinicians and the media, contributes to clinical guideline reviews, and participates in policy discussions to promote rigorous research standards and safer care pathways.

Experience over many years has demonstrated that biomedical research progress must be accompanied by reform in education, clinical guidance and service structures. Without this, scientific advances cannot translate into improved care or protection from harm.

## RECENT PARLIAMENTARY ENGAGEMENT — WESTMINSTER HALL DEBATE (NOVEMBER 2025)

Having contributed multiple times to previous parliamentary debates, in November 2025 Invest in ME Research provided another detailed briefing to the Chair of the All-Party Parliamentary Group for ME ahead of a Westminster Hall debate on Government support for people with ME.

Drawing on more than two decades of experience funding and coordinating biomedical research, the charity highlighted the long-standing neglect of ME research in the UK and the absence of strategic implementation. Key points raised included:

- Recognition that decades of underinvestment have slowed progress and entrenched stigma
- The need for government support for the Centre of Excellence for ME at Norwich Research Park
- Commitment to coordinated, long-term strategic investment, including protected research posts and multi-centre studies
- Expansion of existing international collaborative networks rather than creation of duplicative structures
- Recognition of ME as a disabling condition within welfare and benefits systems
- Greater transparency and accountability in government planning for ME research and outcomes

## CURRENT CHALLENGES AND STRATEGIC DIRECTION

ME remains significantly underfunded and under-researched relative to its disease burden and impact on patients, families and healthcare systems.

### Unimplemented parliamentary commitments

A UK parliamentary debate in January 2019 called for increased biomedical research funding, cessation of harmful treatments, improved professional education, and better recognition of ME in social care and child-protection systems. Despite cross-party support, these recommendations remain largely unimplemented more than six years later.

## International underperformance

While countries such as the Netherlands and Germany have committed substantial national investment to ME research, the UK continues to lag behind, leaving patients underserved and scientific opportunities unrealised.

## Structural policy failures

Persistent barriers include late engagement of expert stakeholders, duplication of effective existing networks, and initiatives that prioritise minor system changes over biomedical discovery.

## Reinvention instead of adoption

A recurring feature of UK ME policy has been the tendency to propose new structures, initiatives or coordination mechanisms while ignoring or duplicating those already established and functioning. Invest in ME Research has repeatedly presented workable models — including international research networks, clinician collaboration frameworks and conference-based coordination — yet these have not been adopted, supported or scaled by establishment bodies.

This pattern of reinvention wastes time and public resources, fragments expertise, and delays progress by failing to build on existing knowledge, relationships and infrastructure that have already demonstrated value.

This has become a predictable feature of UK ME policy.

## PRIME and HERITAGE: Mischaracterised Progress

Recent government communications have pointed to the PRIME and HERITAGE projects as evidence of progress in ME research. Invest in ME Research does not regard either initiative as representing strategic or transformative investment in biomedical ME research.

The presentation of such activity as novel or foundational illustrates the broader tendency to reinvent coordination mechanisms rather than recognise and support those already in place.

PRIME, funded through existing Medical Research Council competitive mechanisms, is presented as an infrastructure and collaboration initiative. However, the activities described under PRIME — fostering collaboration, bringing together researchers, and encouraging cross-disciplinary engagement — have already been delivered for many years by Invest in ME Research through its international conferences, research colloquia, and structured collaborative networks, including EMERG and Young EMERG.

In this context, PRIME does not represent new strategic capability, but rather a limited, short-term project replicating functions that the charity has already established and sustained independently, without government funding. It therefore fails to address the core deficit in UK ME research: the absence of dedicated, long-term biomedical research funding and infrastructure.

HERITAGE focuses on service models and healthcare delivery rather than on the underlying biomedical mechanisms of ME. While understanding service provision has value, such work cannot substitute for fundamental biomedical research into disease mechanisms, biomarkers, and therapeutic targets. Without parallel investment in discovery science and clinical translation, service-focused studies risk entrenching care pathways unsupported by robust biomedical evidence.

Taken together, PRIME and HERITAGE illustrate a recurring pattern in UK ME policy: small-scale, time-limited projects are repeatedly presented as progress, while the structural requirements for sustained biomedical research — ring-fenced funding, protected research posts, coordinated infrastructure, and Centres of Excellence — remain unaddressed.

## Lessons from previous initiatives

Experience shows that reports alone do not change practice without funded implementation and accountability; repeated cycles of poorly mandated working groups delay progress; and biomedical evidence must underpin education and care to prevent harm. The charity explicitly stated this back in 2022 prior to the DHSC Delivery Plan initiative – and has subsequently been proven right.

## MYTH VS REALITY: UK ME RESEARCH POLICY

Myth: The UK Government is now investing significantly in ME research.

Reality: UK investment in ME research remains limited and fragmented. Recent initiatives do not represent sustained, ring-fenced biomedical funding at a scale proportionate to disease burden, nor do they provide the long-term infrastructure required for discovery, validation and clinical translation.

Myth: Initiatives such as PRIME and HERITAGE represent major progress in ME research.

Reality: PRIME and HERITAGE are small-scale, time-limited projects funded through existing competitive mechanisms. PRIME focuses on coordination activities that have already been delivered for many years by Invest in ME Research through international conferences and established research networks. HERITAGE addresses service delivery rather than the biomedical mechanisms of ME. Neither initiative constitutes strategic investment in biomedical research or replaces the need for a fully resourced Centre of Excellence.

Myth: New coordination structures are required before ME research can progress.

Reality: Invest in ME Research has established and sustained international research and clinician collaboration for nearly two decades through structured networks, research colloquia and annual biomedical conferences. The principal barrier has not been lack of coordination, but the failure of establishment bodies to recognise, adopt and support existing effective initiatives.

Myth: Service-focused research will resolve the challenges faced by people with ME.

Reality: While understanding service delivery has value, it cannot substitute for biomedical research into disease mechanisms, biomarkers and treatments. Without parallel investment in discovery science and clinical translation, service models risk embedding care pathways that remain unsupported by robust evidence.

Myth: Delivery plans and working groups demonstrate meaningful progress.

Reality: Repeated plans, reviews and advisory groups have not delivered funded implementation or measurable outcomes. Progress requires sustained investment, clear accountability and adoption of proven structures — not further cycles of reinvention.

## FAILURE OF THE DHSC/UKCRC ME RESEARCH WORKING GROUP INITIATIVE

The Department of Health and Social Care, working with the UK Clinical Research Collaboration, convened a ME Research Working Group in 2022 to help in developing an interim delivery plan for ME research. On conclusion in

2024, the initiative produced no substantive progress beyond restating known challenges.

Invest in ME Research participated in the research working group but found that charity submissions were ignored - not discussed or incorporated, transparency was limited, and no funded actions emerged. The process lacked urgency, clear leadership and accountability, reinforcing patterns that have historically impeded progress.

The charity had raised these concerns publicly in 2022, prior to its later inclusion in the DHSC initiative.

This experience underscores the need for future initiatives to be outcome-focused, time-limited and supported by dedicated funding rather than extended exploratory processes.

## KEY POLICY ADJUSTMENTS

- Sustained, ring-fenced, multi-year investment in biomedical ME research at scale
- Government support for the UK Centre of Excellence for ME, integrating discovery science with clinical translation
- Use and expansion of existing international research networks rather than duplicative structures
- Transparent and accountable government strategy with measurable outcomes
- Recognition of ME in disability, welfare and social-care policy frameworks

## CONCLUSION

Invest in ME Research remains committed to driving biomedical discovery, fostering education and supporting collaborative networks to improve understanding and treatment of ME.

In the absence of support from government or public research agencies, Invest in ME Research has deliberately and consistently pursued biomedical progress with limited resources, reflecting a sustained commitment to patients and their families.

Meaningful progress requires coordinated action across research, healthcare and policy systems. Continued delay has entrenched inequality for people with ME and continued missed critical opportunities for scientific advancement and clinical benefit.

## ANNEX: POLICY CONTEXT AND PREVIOUS GOVERNMENT INITIATIVES

This annex provides additional context to support the positions set out in the main document. It records previous initiatives, patterns of policy development, and Invest in ME Research's long-standing contributions to biomedical ME research. The annex is intended for policymakers, researchers, parliamentary staff and others requiring background detail.

## ANNEX A: PREVIOUS GOVERNMENT INITIATIVES ON ME

Over the past decade, a number of government-led initiatives have been presented as steps towards improving ME research and care. In practice, these initiatives have consistently failed to deliver strategic biomedical progress.

### DHSC / UKCRC ME Research Working Group (2022–2024)

The ME Research Working Group was convened by the Department of Health and Social Care in collaboration with the UK Clinical Research Collaboration with the stated aim of informing an interim delivery plan for ME research. Despite extended timelines and extensive participation by charities and researchers, the process did not result in new ring-fenced funding, dedicated research infrastructure, or a funded and enforceable implementation framework.

While the subsequent DHSC Delivery Plan sets out broad intentions and actions, it does not provide the level of resourcing, accountability or strategic coordination required to deliver substantive biomedical research progress. Much of its content reiterates issues and needs that had been clearly articulated many years earlier.

### PRIME

PRIME was funded through existing Medical Research Council competitive mechanisms and presented as an initiative to build collaboration and research capacity. However, the activities described under PRIME closely mirror coordination, collaboration and researcher engagement that Invest in ME Research has already incrementally delivered for almost twenty years through its conferences, colloquia and established European networks.

PRIME seeks to develop coordination and research capacity over a multi-year timeframe. While such outcomes may be achievable, this approach consumes scarce funding and delays progress by rebuilding structures and collaborations that Invest in ME Research has already established and sustained.

**This represents further reinvention that consumes scarce funding and time, delaying progress by reconstituting coordination activity that already exists and is functioning, rather than immediately building on it.**

From the outset of DHSC engagement, the charity repeatedly proposed that the established collaborative foundations it had already created and demonstrated be used as the basis for national research coordination and development, rather than recreating those foundations through a new, time-limited initiative. The decision to proceed with PRIME therefore reflects unnecessary reinvention and avoidable delay.

### HERITAGE

HERITAGE focuses on healthcare delivery and service models. While service evaluation has a role, such studies **do not address the fundamental biomedical questions underlying ME, including disease mechanisms, biomarkers and therapeutic targets**. Without parallel investment in discovery science and translation, service-focused initiatives risk reinforcing care pathways that remain unsupported by robust biomedical evidence.

## ANNEX B: REINVENTION AND FAILURE TO BUILD ON EXISTING CAPACITY

A consistent pattern in UK ME policy has been the tendency to propose new structures and initiatives while ignoring or duplicating those already established and functioning.

For nearly two decades, Invest in ME Research has developed and sustained effective mechanisms to address fragmentation in ME research, including:

- Annual international biomedical research conferences and research colloquia
- European research collaboration through EMERG and Young EMERG
- Clinician collaboration via the European ME Clinicians Council (EMECC)
- Development of research capacity and infrastructure at Norwich Research Park

Despite the existence of these working models, establishment bodies have repeatedly chosen to develop parallel initiatives rather than adopting, supporting or scaling existing capacity. This approach has resulted in duplication of effort, inefficient use of resources and loss of institutional memory.

Failure to build on established expertise has delayed progress as much as underfunding itself and continues to impede effective translation of research into clinical benefit.

## ANNEX C: INVEST IN ME RESEARCH – TRACK RECORD AND STRATEGIC APPROACH

Invest in ME Research has operated continuously for over twenty years with a clear focus on biomedical research, international collaboration and education.

Key elements of the charity's strategic approach include:

- Long-term commitment to biomedical science rather than short-term or flawed behavioural models
- Development of European research and clinician networks to overcome isolation in the field
- Support for early-career researchers to build future capacity
- Focus on Centre(s) of Excellence as the most effective mechanism for sustained discovery and translation

The charity's work demonstrates that progress in ME research is achievable when investment is strategic, sustained and grounded in existing expertise rather than repeatedly reinvented structures.

One is left to wonder what could have been achieved had this approach received more support and funding.

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