



# Invest in ME Research

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## Invest in ME Research

### Observations from and following the final meeting of the UKCRC ME Research Working Group

**May 2024**

The final meeting of the Department of Health and Social Care (DHSC) / UK Clinical Research Collaboration ME/CFS Research Working Group (RWG) project took place on May 10, 2024, marking two years since the project's inception.

Due to some technical issue with the session, the charity's representative was muted during the meeting, able only to listen – somehow a symbolic reflection of the experiences of the past two years in the Research Working Group (RWG), during which our submissions were either not distributed or not discussed, and our perspectives seemingly ignored.

#### **Interim Delivery Plan and Online Survey**

In this last meeting, a status update was provided by UKCRC on the interim delivery plan, using results from the online survey conducted in late 2023 and given in a subset of slides.

Our view from this brief presentation was that nothing new had been discovered that was not already known by us, and patients and carers. We commented in this way in our submission to that survey in 2023 [[6](#)].

The findings could have been articulated at the project's outset two years ago—or even earlier—reinforcing our belief that this project has merely served as a holding tactic, delaying real progress.

We were informed that the survey results would remain unpublished until the final report is completed. This prolongs the lack of transparency, keeping everyone in the dark unnecessarily, and typifies the project's overall approach, characterised by a lack of urgency and ineffective leadership.

## False Hope?

This project was initially promoted by an ex-minister (and soon to be ex-MP) with much fanfare, promising significant changes. However, it has resulted in further delays in resolving known issues, wasting resources, effort, and lives.

We were already aware of the recurring themes of chronic underfunding, bureaucratic inertia, and a shameful lack of urgency — all of which stymie real progress.

Despite the time and effort invested, the project has failed to produce any new insights or meaningful progress in tackling these issues and there is little indication that things will change anytime soon.

This project was set up with scant regard for the urgency to address ME-related issues and little transparency for those with ME, who have been denied visibility of meeting minutes and provided minimal information about the project's status. Combined with lacklustre leadership and no real drive for progress or direction for this RWG, it has resulted in an uninspiring and pointless exercise.

## A Recap - Reflecting on Past Predictions

The outcome of this project sadly aligns with IiMER's reservations made in June 2022, when it had all been set up and before we were even invited to join. [[1](#)]

We expressed scepticism about the project's potential for meaningful progress, fearing it might become another futile exercise, as the proposed working groups and project structure seemed unlikely to achieve more than what existing knowledge and ideas already offer. Taking two years to produce another document would simply delay taking action to resolve the issues.

We doubted the timescale for the project in this context and the major constraint that was tucked away in ex-minister Javid's announcement - no new funding.

The Terms of Reference for the RWG had already been set by others before the first meeting to which we were invited in September 2022, but we nevertheless commented with recommendations [[2](#)] such as making meeting minutes public, developing ME specialisms, prioritising urgent research funding.

Importantly, we emphasised the need for a short delivery timeline, given that many patients have suffered for decades. Urgent funding and initiation of research were crucial.

We queried the need for raising awareness of research into ME among funders and the research community, given that the MRC had a highlight notice present for 13 years without monitoring, status updates, or checkpoints. The problem seemed to lie with those promoting the need for research, not the researchers themselves.

We stated the need to consider existing developments rather than reinventing them.

We published and input a document to the group in September 2022,

**"Our View on a Different Approach"**[\[3\]](#),

and recommended three points for rapid progress:

- Use and expand the centre in Norwich with additional funding to act as a focal point for research.
- Use the Dutch research agenda as a basis to avoid unnecessary duplication and build on a European model, potentially attracting more funding.
- Push back to the UK government for up front funding, as done by the Dutch government and NIH in the USA.

Our document was not distributed or discussed. We again submitted this yet all these suggestions were disregarded. Professor Carding's valid proposals in October 2022 faced the same fate. [\[4\]](#)

The Draft Interim Delivery Plan on ME/CFS published by DHSC in September 2023, with an announcement of a survey for people to input their experiences of ME, contained little new information. The Norwich Research Park's potential remained unrecognised, delaying progress. [\[5\]](#)

A year had passed with nothing achieved that could be termed a change for people with ME.

In October 2023, we stated our lack of confidence in this group producing anything tangible [\[6\]](#)

This was further illustrated this year as the project's conclusion approached in April when a subgroup of participants proposed a last-minute document, separate from the RWG's work, focusing on post-viral conditions and diluting the focus on ME. This document, compiled without our involvement, proposed a research hub or consortium for post-viral conditions that included ME.

This might have seemed practical. However, this project was set up by DHSC/UKCRC to address ME - not look for solutions for all other conditions.

Having the condition watered down and absorbed into a nebulous trough of various conditions under a post-viral catch-all title would, we feel, risk seeing ME ignored or even erased? Has this tactic worked so far for ME with the comparison with long covid?

Successive governments and funding agencies have done their best to ignore ME for decades. Let the government and UKRI tell severely ill ME patients that they will again be confronted with more lost years due to fudge and inaction to tackle directly the lack of research into ME.

## Summary

Two years and nothing of substance.

- **Lack of Progress and Urgency:**

- Over the two years, no new insights were discovered, and no significant changes were implemented. The project exhibited a lack of urgency in addressing the challenges faced by people with ME.

- **Absence of Transparency:**

The process was opaque, with minimal communication and engagement with ME patients. Our impression was that decisions and actions seemed to be taken in the background, dominated by certain elements in the RWG.

- **Ineffective Leadership:**

Leadership failed to drive any real change or progress. There was no inspiration, no drive, complacency in dealing with the urgency for people with ME, and an acceptance of standard approaches dictated by the UKCRC and funding agencies.

- **Lack of Ambition or Direction:**

The initiative, launched by a former minister who had not seemed to address problems with ME in all his tenure as health minister, lacked ambition and has ultimately produced no tangible results, giving false hope and wasting time and resources. Meek acceptance of existing constraints without challenge only has not served people with ME well.

## **Recommendations and Future Direction**

Invest in ME Research has consistently advocated for a more efficient approach, emphasising the need to leverage existing resources, such as those at Norwich Research Park, and utilising current infrastructures, and fostering international collaboration using the existing links we already have in place between European and international institutes.

A fresh and ambitious, yet pragmatic approach is essential, one that builds on existing research and resources. Here is what we proposed:[\[3\]](#)

- **Centres of Excellence:**

- Establish and adequately fund Centres of Excellence for ME leveraging existing infrastructure and collaborations - starting with the centre in Norwich Research Park, which has already made significant strides in ME research.

- **Collaborative Approach:**

Foster collaboration within the UK and internationally to accelerate progress. Base research on the existing Dutch research programme to save time and consider joining forces to create a Europe-wide strategy. Utilise existing networks - the European ME Research Group (EMERG) and Young EMERG to provide a solid foundation for such collaboration.

- **Focus on Implementation:**

- Shift from endless discussions to actionable plans. Implementing a three to five-year strategic initiative, with regular reviews, will ensure a more dynamic and responsive approach.

- **Utilising Established Resources:**

- Rather than reinventing the wheel, the government should build upon what has already been developed. The Quadram Institute, for example, is conducting the only clinical trial for ME in the UK and has extensive links to European and international research networks.

- **Challenging Constipated Funding Processes:**

Challenge the DHSC regarding funding – nothing can be achieved without a commitment of specific funding. This should have been addressed from the outset, as we proposed. Examine the MRC, NIHR, and DHSC for their negligence in monitoring ME. The current infrastructure of having researchers apply for non-existent funding for disparate projects without any strategy or collaboration will consign ME to another decade of ignorance, misinformation, and apathy from these establishment organisations.

## **Conclusion**

The DHSC's two-year project has concluded with little to show, merely reiterating known issues without providing new solutions or fostering real progress.

Despite urging the adoption of a focused, collaborative approach leveraging existing resources, particularly the established foundation in Norwich Research Park, our proposals were disregarded and not discussed. This foundation includes a research base, ongoing clinical trials, European and international collaborations, and a network of researchers and clinicians. Without such measures, meaningful strides in understanding and treating ME are unlikely in any short term.

Ignoring what we have already developed was the norm during the last two years.

Our proposal to push back on the lack of new funding was ignored, and our views were often omitted from the sparse meeting minutes, which were never made publicly accessible.

Over the two years, no new insights were discovered, and no significant changes were implemented, reflecting the project's lack of urgency or effective leadership.

The project's inefficiency and lack of direction, producing nothing new, exemplify the need for a fresh start.

This initiative, created by Javid in May 2022, planned for two years of discussions.

Why two years when the problems and solutions were already known?

Why not six months, or three months?

It is evident that such a timeframe was strategically chosen to delay progress, possibly aligning with political agendas and economic constraints.

If one wishes to bury a topic, or at least curtail any real progress, then set up a two-year project that will achieve nothing but another document, just in time for a certain general election and, possibly (almost definitely), a new government, and an economic situation that will again plead lack of funding and other priorities.

Any document (containing what has already been known and documented for many years) is left on the shelf for another period of time.

And so it goes on.

The CMO report was written 22 years ago and so little has changed.

As the project failed, Invest in ME Research remains committed to pushing for a focused and rapid approach to ME research.

Despite the setbacks, we will continue to concentrate on existing collaborations using whatever resources we have for the benefit of all those affected by ME – and take action where we can.

Following the final meeting in May 2024, Invest in ME Research offered to host a meeting of researchers with the NIHR and MRC during our International Conference Week in June at the Wellcome Genome Campus, potentially including some international researchers and agencies attending our BRMEC13 colloquium.

This offer was not even acknowledged by these agencies!

After waiting long enough for a reply we eventually had to rescind the offer as our reservation of meeting facilities had expired and we had to continue conference week planning.

Another opportunity lost.

Meanwhile, in the time it took the DHSC/UKCRCR project to get nowhere, the National Institutes of Health (NIH) used half that time to set up working groups and create a roadmap for progress.

IiMER has now arranged a separate meeting to discuss advancing clinical trials to expedite progress.

How many more failures will it take for real change to occur? How many more lives will be wasted?

Invest in ME Research remains committed to driving change, echoing our chairman's sentiments over many years that "we have to do it ourselves."

## References

For more detailed insights and background information, please refer to our published articles and submissions:

1. [Initial Critique - June 2022](#)
2. [Input to our 1st UKCRC Working Group meeting September 2022](#)
3. [Input to UKCRC ME Research Working Group - Our View on a Different Approach](#)
4. [Input to UKCRC ME Research Working Group](#)
5. [Observations on DHSC Interim Consultation document](#)
6. [Research Working Group - Status Update - November 2023](#)



## Further Information

- [RESTORE\\_ME Clinical Trial](#)
- [European Research Collaboration](#)
- [Dutch research agenda](#)
- [UK Centre of Excellence for ME](#)
- [Young/Early Career Investigators Workshops](#)
- [Our proposal in the UK parliamentary debate 2019 to provide funding for research into ME year for five years](#)
- [#InvestinMEresearch2022](#)
- [Invest in ME Research's Proposed UK Government Department of Health and Social Care Statement on ME](#)

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