



Invest in ME Research

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Input to UKCRC ME Research Working Group

Meeting November 2023

This document carries comment from UK charity Invest in ME Research (IiMER) with the recent meeting of the ME/CFS Research Working Group held on 24 November 2023.

Recap

Invest in ME Research was not initially invited to be involved in the initiative being run by the UK Clinical Research Collaboration (UKCRC) [[1](#)]. The objectives and terms of reference and structure of working groups were already decided in previous meetings that had been held prior to our invitation to join.

In our first submission to the DHSC research working group in September 2022 [[2](#)] we requested that minutes of all meetings be made public.

This was declined.

We therefore decided then to document our involvement in order to allow some visibility to what was occurring. [[4](#)]

In our first submission to the DHSC research working group in September 2022 [[2](#)] Invest in ME Research also highlighted our view of the most rapid and productive pathway to achieve change to the research environment that would expedite research and discovery for ME.

To expedite progress in research we should use what exists already. This included the centre of excellence being founded in Norwich Research Park, as well as an existing plan for research that had already been developed by the Dutch research agency and which contained a possibility to use a research plan

that was developed in consultation with patients and which could be broadly adopted, or even joined with a UK research agenda.

We also stated that we felt that the group should push back to the government immediately and state that nothing could be done unless funding was already made available for these developments.

The document was not distributed or discussed. We requested that this be done by the secretariat. It was also brought up at the beginning of 2023, prompted by another member who mentioned it again.

We are still uncertain if it was distributed fully – it has never been discussed. It was, however, immediately made available on our web site and social media [3].

We summarised with this paragraph –

We need to get going with research and increase the capacity – which then generates more interest, funding, collaboration.

This is urgent and the UKCRC Working Group needs quickly to move from a mode of documentation to one of action.

We should use what we have created already as a base and model.

So our suggestions are –

- Use what has already been developed and expand and augment the centre in Norwich with additional funding to act as a focal point for research, which will then be useable as a way to achieve the other objectives
- Use the Dutch research agenda as a basis to develop the above. Avoid unnecessary duplication and build on a European model for research, which may in turn attract more funding.
- Push back to the UK government stating that funding is required up front to initiate this (as has been performed by the Dutch government and the NIH in the USA already)

August 2022

In the October 2022 meeting -

we again suggested to the UKCRC working group that a statement should be issued to the health minister that funding for research should be established and made available up front - already before any plan is established.

If capacity is required to be increased in the research community and if interest and awareness is required to be gained then funding is a pre-requisite.

Otherwise, the end result will just be more documentation that will be left on the shelf.

None of the above will be possible without required funding. [5]

Since then we have participated in some of the discussions with a feeling of frustration that nothing much is being achieved (4).

The only tangible output seems to be the DHSC Interim Delivery Plan report that contains little, if anything, that was not already known - though some actions contained in the report will be welcomed, if actually enacted with a sense of urgency, rather than suggested and ignored

More delay while this survey is analysed - Urgency still not a priority overall and still no sign of funding has been promised for research

The existing research centre in Norwich Research Park has not been recognised and its potential for rapid progress in research is therefore lost, with further delays to progress

There now seems to be an intent to supply a set of recommendations for research at some time in 2024 - and no knowledge of what will definitely be implemented, what the content of planned education and information will include, and no definite research strategy being funded

Eighteen months have passed since Secretary of State for Health Javid's announcement with nothing yet achieved that can be termed a change for people with ME

On 24 November 2023, we participated in an update meeting of the research working group where we heard that recommendations would be formed to be put to DHSC by May 2024, based on what had transpired in meetings up to that point, and any actions that had been taken.

This will have been the output from two years of discussions.

We passed these comments -

- We did not believe and had no confidence in this plan achieving anything
- We stated that we thought recommendations would just be another document that would achieve nothing and, with a pending election becoming imminent, the recommendations would be subject to whatever government was elected and the policies and decisions it pursued.
- We stated that just passing recommendations, without funding being allocated immediately, would simply place us in the same position as we are in now where researchers would be funded in small amounts, according to individual applications and that likely only favoured researchers would be given funding.
- We also said that it was still at the mercy of MRC peer reviewing – and we all knew how suspect that has been for ME over the years.
- Just repeating the current situation with a few more web site pages updated, a dusting off of the eleven-year-old highlight notice and a few more documents to be added would achieve nothing.
- We reaffirmed our view that the document we submitted back in September 2022 in the first meeting to which the charity had been invited was still, in our view, the best way forward. These contained three recommendations –
 - - Use what has already been developed and expand and augment the centre in Norwich with additional funding to act as a focal point for research, which will then be useable as a way to achieve the other objectives
 - - Use the Dutch research agenda as a basis to develop the above. Avoid unnecessary duplication and build on a European model for research, which may in turn attract more funding.
 - - Push back to the UK government stating that funding is required up front to initiate this (as has been performed by the Dutch government and the NIH in the USA already)

- We reiterated that this document had not been distributed, even though we had mentioned this in subsequent meetings, and was only mentioned again at the beginning of the year by one other participant.
- We have never seen any evidence that our recommendations were considered.
- We stated that we have the centre already firmly founded in Norwich Research Park with research at Quadram Institute and UEA, a university and university hospital collaborating, an ME clinic with clinicians and physios already involved, with more funding and research on its way; that we have European and international collaboration already formed with European ME Research Group and a European young/early career researcher network and clinicians group formed. We hold annual research colloquiums with researchers from around the world. Therefore, the foundations were already in place and operating – with only funding required.
- All of this has been ignored.
- We believe that the Norwich Research Park environment with Quadram Institute and UEA offers the best location, the most expeditious pathway for progress in research and building of capacity and awareness, and the best value for (limited) funding to develop further the centre of excellence. Yet we have seen how our views have been ignored. So we proposed that the other research locations represented at the meeting could come together with the existing Norwich centre and produce a joint proposal for funding the Norwich centre and these other locations as centres of excellence for ME.
- We also stated that the MRC highlight notice was ineffective and useless, despite some comment in the group seemingly believing that it would achieve something.

The APPG for ME now recognises the necessity and benefits of the Centre of Excellence for ME.

Others are finally acknowledging the concept, even disingenuously adopting the term for their own purposes, despite never supporting our proposal for the Norwich centre since our work began in 2011.

While always hopeful, we remain skeptical of the DHSC initiative's progress over the past eighteen months, disappointed at the lack of urgency and vision for real progress.

We have provided feedback on the interim survey plan (4), but actual action seems further delayed.

We await developments following our expressed views in the meeting.

Despite our ongoing advocacy, development, and funding efforts since 2011, the apparent solution of a UK/European Centre of Excellence for ME in Norwich Research Park is being overlooked.

Facilities, well-developed research, and established collaborations are already in place. While we continue to support what we see as an existing research centre with the potential to become the leading hub for biomedical research into ME in the UK and Europe, the missing piece remains: funding.

It should have been different.

We wrote the following back in June 2022 [1] –

What is coming down the line with almost a cast-iron guarantee will be continued doubts about the government, with ministers potentially coming or going, an election, a cost of living crisis that makes all new projects suspect and leading to research funding being even scarcer.

What is also pertinent though is to realise that Mr Javid has stated that no new funding will be available for research into ME – as there apparently exist existing pathways to access funds already. Mr Javid has also recently said the NHS does not need more money.

So it poses the question of what is new with this new initiative?

We only hope that this will not turn out to become another failure that might string this along for years, announce a little bit of funding for diverse projects and make it look like something is happening and progress is being made.

We do not need another merry go round where it appears that things are changing but where we end up in the same place.

What is needed is a fresh start that will fund what we have already developed. It would be quite easy to come up with a plan already that would work as the necessary working relationships with others already exist.

There is already established a foundation in Norwich Research Parkn to build upon and develop that would save years of new discussions. We have a base of research, funded researchers and projects underway, a clinical trial being started with additional research being added,

European and international collaboration, a network of European researchers and clinicians, interaction with an international family of researchers and national agencies such as NIH and CDC.

So, there is a really good foundation already in place that has a centre for ME where we have the basic components and fundamental research taking place – a great model and base for the future. This could and should just be built upon.

It would be foolish to ignore what has been established already in Norwich Research Park, with Quadram and UEA and university hospital and with a supporting ME clinic - we have those components and internal support.

There will be no justification for not including them in any discussions.

Rather than making noise and wasting scarce funds on repeating what we already have, or reinventing what has already occurred, one could take the initiative and build on what we have.

Yet it would not surprise us that some will avoid recognising the potential that we have already in place – and will likely just try to reinvent everything in a location of their choosing.

What ought to be stated at every meeting of any working group is that this matter is urgent and does not need endless meetings spanning years which ultimately lead to little real progress. We should not be pumping egos and allowing organisations to look important just to continue to exist.

November 2023

References

- 1 [Sajid Javid – 2022 Statement on ME/CFS](#)
- 2 [IiMER Input to 1st September 2022 UKCRC Working Group meeting](#)
- 3 [Input to UKCRC ME Research Working Group - Our View on a Different Approach](#)
- 4 [Overview of UKCRC Comments](#)
- 5 [An Overview of Requirements](#)
- 6 [Input to APPG for ME November 2023](#)

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