



# Invest in ME Research

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## Invest in ME Research

### Input to UKCRC ME Research Working Group

This document concerns Invest in ME Research's input to the UK Clinical Research Collaboration ME/CFS Research Working Group – from August 2022.

We feel that what exists already needs to be considered.

### Our View on a Different Approach

With an initiative such as this UKCRC Research Working Group for ME/CFS<sup>1</sup> there seems to be a tendency to create a wish-list of many different requirements being put up and yet without a realistic plan to achieve in the current environment that is adequately backed by financial support – i.e. funding to make it happen.

Due to the failures of establishment organisations over the years to address this condition there is so much to do that it might be seen as a green field site for development.

At the end of the two years mentioned as a timeframe in the UKCRC TOR document – another two years where patients are waiting – there will be a new government, possibly new covid strains that will continue to emerge, long covid issues, cost of living issues, Brexit fallout continuing, war uncertainty – and a fair chance that large amounts of funding are not available.

Yet without funding these are all just documents and there is little likelihood of a comprehensive strategy being enacted.

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<sup>1</sup> The charity prefers the acronym ME for myalgic encephalomyelitis. ME/CFS is frequently used in this document to avoid confusion with terminology used by UKCRC

There is one area that we have not seen in the documents supplied by the UKCRC – i.e. what we already have in place.

In the context in which we find ourselves (little capacity, little or no funding) then the quickest way to build and develop is to avoid reinvention and use what we have already – what has been funded or developed and holds potential for developing more rapidly than spending two years writing documents.

### **Norwich Centre of Excellence**

Since 2012 we have stated that we need a centre of excellence for ME – and we have already in place all the functioning components, working together, if still underfunded.

We should use what we have developed already – and what we have in Norwich Research Park (NRP) is already impressive and covers practically many of the components that are required to avoid calling for huge investment from day 1.

Our suggestion is at NRP where we already have an ongoing research programme, new investment, established years of recognition for the disease and plans to build more.

The following already exists with components already in place

- Experienced team of world class researchers
- Established research into ME
- 5 PhDs funded
- Inter-departmental collaboration already established
- Collaboration with major university and other institutes already established
- University hospital already collaborating
- The only UK clinical trial for ME funded and starting – one of only a few in the world
- A Clinical Trials Unit in place and collaborating with the institute
- Medical school (where the charity has already funded medical students intercalating in their degree course and participate in research and education about ME)
- Biorepository / tissue bank

- Objective and innovative outcome measures being developed in association with other disciplines and companies
- Links and funding with major funding organisations already – most recently £500k invested in facilities to support the clinical trial
- Already established networks to funders and media
- Collaboration with long established ME clinic with thousands of ME patients already
- Clinicians working with researchers and now also examining long covid patients
- GP champions for ME with NHS
- Links and collaboration to/with other major European institutes and chairing European ME Research Group which involves researchers and clinicians
- Links to European ME Alliance patient network
- Major annual international researchers' colloquium organised for twelve years
- Other international links to researchers and agencies (e.g. NIH) already in place
- Further research into ME soon to be announced and more funding on its way for new and associated research

We have already seen in the time that we have been proposing and developing the centre in Norwich (since 2012) that

- It has encouraged and supported researchers to develop high quality research into ME/CFS co-produced, from inception to dissemination, with people with lived experience of ME/CFS
- It has proactively fostered increased capacity among the research workforce, by bringing in other research disciplines as required to answer the research gaps in this area
- It continues to discuss whether there are skills gaps to improve capability, and how these might be addressed (mainly by investment)
- It has raised awareness of ME across the research park, and beyond, and has built trust with patients (often charity lead)

- It has raised awareness of research into ME – by public meetings, by the Invest in ME Research international conferences and research colloquiums (these have always focused on bringing together researchers, European charities and patient organisations and people with lived experience of ME.
- It has overcome stigma by emphasising the science that is being applied by world class researchers and institutes and demonstrating that ME is a real disease

Using the existing setup will save time and funding and be the focal point for ideas for further research in a joined up strategy.

“With over 3000 scientists at the Norwich Research Park, consisting of 4 world leading research institutes, a university and a teaching hospital, it is one of Europe’s largest single-site concentrations of research in Food and Health and Environmental sciences.

Having academic excellence across a range of diverse, but related fields, in one location is a very powerful way to deliver a step-change in potential outcomes across a number of health issues.

Importantly, the new centre for food and health, due to open at the end of 2017 at the Norwich Research Park, takes co-location to a new level as it uniquely integrates academic excellence with clinical expertise; by bringing together the Institute of Food Research with aspects of the University of East Anglia’s medical school and science faculty with the Norfolk and Norwich University Hospitals’ gastrointestinal endoscopy facility, working alongside industry.

The new Institute will provide a novel holistic, systematic and integrated approach to deliver faster innovation as well as helping to inform government policy on a range of gut and diet related issues including M.E.

The development of this new centre, together with the other expertise and facilities located at the Norwich Research Park, puts it in a very good position to lead a **UK and European Centre of Excellence for biomedical research for M.E.** to provide possible prevention and solutions.”

**Professor Ian Charles, Director Quadram Institute Bioscience**

**Journal of liME Abstract 2015**

The NIH took this idea and funded four centres that would collaborate. They have now been running for several years and a new tranche of funding has now become available.

## Dutch Initiative

Looking again at what already exists then we believe that we should take from what the Dutch are doing now.

They have already agreed a research agenda (doing much of the work outlined by the UKCRC documents) and up-front funding has already been committed by the Dutch government.

The Dutch agenda is based on a 10-year research programme with €28,5 million to build research infrastructure: transdisciplinary, international patient participation and patient cohorts.

The Dutch research agenda has the following points already –

- A Literature study and engagement with Dutch scientists in preparing research infrastructure
- A 4 phase research agenda consisting of –
  - Phase 1 Fundamental research
    - (Chronic) immune activation, immune metabolism & neurological deficiencies
    - Brain imaging research for tracking disruptions in brain metabolism
    - Cellular energy metabolism in relation to cell function
  - Phase 2 Epidemiological research
    - Origin of ME/CFS: (epi)genetic factors, environmental factors, infectious causes;
    - Longitudinal research on the course of ME/CFS and/or prognostic studies;
    - Research on a better description of ME/CFS, for a better diagnosis. Subgroups and/or co-morbidities.
  - Phase 3 Clinical research
    - Diagnosis of ME/CFS; physiological tests like exercise tests and definition of biomarkers;
    - Therapies tested in other diseases, or abroad;

Treatments alleviating important symptoms.

- Phase 4 Improving clinical practice
  - Implementing (new) biomedical knowledge on ME/CFS among Dutch health professionals, medical examiners, medical guideline developers, etc.;
  - Improving the discourse on ME/CFS in the Netherlands.

The centre in Norwich is already in contact with Dutch researchers.

The European ME Research Group has already had discussions on planned research and has a member in the Dutch working group already.

The European ME Alliance (a recognised umbrella organisation for European ME national charities and organisations) has members in the Dutch working group already.

We could perhaps synergise the efforts and come to an agreement with the Dutch. This could be used in conjunction with the centre in Norwich Research Park – and even joined with any UKCRC initiative.

We feel that with the research environment already set up in Norwich and with collaboration with the Dutch research agenda then this could be an effective and more rapid way to initiate an approach to improve research capacity, increase interest in research, generate more funding for research into ME and assist in removing establishment stigma regarding this disease.

Of great importance, it addresses the urgency required to make progress in treating this disease.

## **Funding**

Of course, what is required is adequate funding – not piecemeal funding awards to disparate projects that are isolated from a longer term view.

We already mentioned the example of EMERG seeking funding where the assessment process failed.

We believe that the UKCRC Working Group should already push back to government to get initial funding to build up the centre(s) mentioned above.

Sajid Javid announced there would be no new funding specifically for ME as, he stated, existing funding streams are sufficient.

That patently has not been true or sufficient for ME over decades.

In 2019 for a parliamentary debate we suggested [1] that, to realise real progress and develop effective treatments for ME, then ring-fenced funding of at least £20 million a year for five years for a strategy of biomedical research into ME could be set up.

This £100 million would likely end all of the years of suffering of people with ME and give hope for the future. This is a relatively small amount. At the time the government had doubled its contribution to brain cancer research, on the spur of the moment, following the death of one MP by pledging an extra £20 million on top of its existing commitment. It can surely do this to help over 200,000 citizens suffering from ME and the millions of carers and family members affected by the consequences of the disease.

This begins to create capacity and interest and allows other aims to be developed and achieved.

Predictably (and predicted) the government merely paid lip service to this document and the debate – and our fear is that (as always is the case for ME) that attitude will continue.

### Summary

So, to summarise, a lot of work has already been performed and we can synergise the research in order to make more rapid progress.

We believe this way forward holds out the best hope of rapidly moving things along and should form part of the efforts of this Working Group.

The draft proposal received is instead suggesting more subgroups but the reality is that nothing may get done. Adding on extra working groups may do nothing

but prolong discussions without any certainty of achieving anything more than documentation.

It is not a green field site as no funding is guaranteed.

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).

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## REFERENCES

1. [IiMER Parliamentary debate document](#)

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