



## ME/CFS Biomedical Partnership to apply for funding

Led by biomedical researchers and patient representatives, including Action for M.E. Chief Executive Sonya Chowdhury, a newly established group called the ME/CFS Biomedical Partnership has announced that it will apply for research funding from the Medical Research Council (MRC) and the National Institute for Health Research (NIHR).

As the Medical Research Council (MRC) [highlights on its website](#), it will fund a workshop later this month, to help the Partnership explore how to make its application as robust as possible.

The Partnership has published a Q&A; further updates are expected as the project develops. In summary:

- The Partnership will apply for funding for a large genetics study as well as an expansion of the [UK M.E./CFS Biobank](#)
- If funded, the genetics study will require saliva samples from 20,000 patients.
- The study will look for the potential genetic cause(s) of M.E./CFS.
- Submitting a sample will be made as easy as possible in order to enable as many patients as possible to take part.
- Patients, and their representatives, will form an important part of the Partnership.

This project is the culmination of work by members the [UK CFS/M.E. Research Collaborative \(CMRC\)](#) of which Action for M.E. is a founding and active member.

Prof Stephen Holgate, CMRC Chair, says: *“The CMRC was set up to trigger new scientific directions and build research capacity. Over the last seven years, we have run five successful conferences, [with a sixth planned for March 2020](#), fostered new collaborations and have established a series of working groups to drive forward specific areas such as medical education. We have worked in collaboration with researchers, the patient advisory group, charities and mainstream funders throughout this time and are delighted to see that our collective effort has led to the ME/CFS Biomedical Partnership being established. This new team will now work together to submit an application for funding to drive forward this ambitious project.”*

Lead investigators for the Partnership are human genetics specialist and CMRC Deputy Chair, [Prof Chris Ponting](#); and clinician [Dr Luis Nacul](#), who leads the CureME team at the UK M.E./CFS Biobank.

Dr Nacul says: *“The CureME team at the London School of Hygiene & Tropical Medicine is excited to announce that it is collaborating with the CMRC, to submit a research proposal on M.E./CFS to the Medical Research Council and the National Institute for Health Research. The CureME team is a critical partner in this informed and competitive submission, and is focusing at this early stage on developing the research proposal and ensuring the accurate categorisation of people with ME/CFS, using diagnostic criteria harmonised with our own protocols and with the US Centers of Excellence for ME/CFS (NIH funded).*

*“We will also continue our own research within the London School of Hygiene & Tropical Medicine, supporting transparent, multidisciplinary research informed by and for the benefit of people with ME/CFS. We are confident that this collaboration will help to accelerate much-needed research in this field, enabling further biomedical studies into well-defined ME/CFS.”*

Action for M.E. is delighted that our Chief Executive, Sonya Chowdhury, has been invited to be Chair of the Patient and Public Involvement (PPI) Steering Group, and one of two PPI Co-Investigators, alongside Andy Devereux-Cooke. Other members are:

- Margaret, Countess of Mar, on behalf of Forward ME

- Charles Shepherd, on behalf of the ME Association, a founding charity member of the CMRC
- representative from the CMRC Patient Advisory Group.

PPI means that patients and members of the public with relevant experience contribute to how research is designed, conducted and disseminated (it does not refer to those giving samples for a study, who are research participants).

As explained in Q10 of the Q&A, the PPI Steering Group met for the first time this week. Terms of reference will be agreed and made available as soon as possible, with key documents and minutes from meetings shared throughout the project to ensure transparency.