

## **ME/CFS Biomedical Partnership Patient & Public Involvement (PPI) Steering Group Update**

### **Introduction**

A workshop, hosted by the Medical Research Council (MRC) and the National Institute for Health Research (NIHR) was held on 25 November 2019 and was attended by 30 people with ME, carers, scientists/researchers, charity representatives and MRC/NIHR representatives.

The purpose of the workshop was to assist the research team management group (Prof Chris Ponting, Dr Luis Nacul, Andy Devereux-Cooke and Sonya Chowdhury) alongside Biomedical Partnership colleague investigators in developing a fully informed and competitive proposal and make recommendations to improve the research proposal. Following this workshop, a research application will be submitted to MRC and NIHR in January for consideration for funding, following peer review. You can read more about the project in [Simon McGrath's blog](#) and on the [FAQ](#) produced about the project. An update to the FAQ will be produced soon.

For those PPI Steering Group members present, there was a unified view that the workshop delivered in its purpose and was a positive, inclusive experience with patient and carer involvement at its heart.

### **What was discussed at the workshop?**

The workshop was overseen by an external facilitator from [Knowinnovation](#) to help ensure that all participants were able to participate effectively and keep the group to task. After introductions from the MRC/NIHR and the Management Group to set the context, there were two sessions designed to help explore different aspects of the research methodology.

#### **Session 1: Case definitions and PPI**

- What is the most appropriate definition of ME/CFS that will be used in this project?
- What are the ideal inclusion/exclusion criteria and how are participants matched to this?
- What is the most appropriate method for recruiting patients into the study?
- What are the risks in recruitment and how should these be mitigated?
- What should PPI look like for the project?

Workshop attendees supported the Management Group's proposal that people should meet the Canadian Consensus Criteria and/or the Institute of Medicine criteria. You can read more about the different case definitions [HERE](#).

**Have your say by voting and letting the PPI Steering Group know your thoughts: [LINK HERE](#)**

#### **Session 2: Methodology and Governance**

- What should an ME/CFS platform look like?
- What should the balance be between GWAS and more in-depth biomarker studies?
- What further research opportunities are there for each of these cohorts?
- How should frozen samples be biobanked (single or multiple site)?
- What should the governance for access to the samples and data look like?

The group discussed the above questions alongside how to prioritise the different aspects of the research and the budget. It was agreed that we need to craft a scientifically robust GWAS application but the more detailed costs now available most likely mean that we cannot also expand the biobank with samples other than saliva. There was consensus that we need to prioritise the GWAS work. There were lots of other suggestions and recommendations from individual participants which the Biomedical Partnership Management Group will now consider.

At the end of the workshop, the importance of this invited application to not only deliver a high-quality genomics project but to also create a new pathway for future research and research funding in the UK was re-stated.

**PPI Steering Group Members:**

- Sonya Chowdhury (Co-Investigator; Action for M.E.; UK CFS/ME Research Collaborative (CMRC) founding charity representative)
- Andy Devereux-Cooke (Co-Investigator; CURE-ME Biobank Steering Group patient representative)
- Jim Wilson (UK CFS/ME Research Collaborative (CMRC) Patient Advisory Group representative)
- Countess of Mar (Forward ME representative)
- Dr Charles Shepherd (ME Association; CMRC founding charity representative; CURE-ME Biobank Steering Group Chair)