UK Ecosystem Report

ME/CFS & Long COVID



CrunchME #ThereForME

Rory Preston, Karen Hargave, Emma Gore-Lloyd,
Oonagh Cousins, Michael Natt

Interim Report | Version 25.03.17

This report provides an overview of the ecosystem emerging in the UK focused on addressing and solving ME/CFS & Long COVID

Slides	Contents
2-5	Biomedical Research Groups
6-8	Clinical Treatment Trials
9	Tech & Biotech Companies
10	Specialist Clinicians & Clinics
11	Scientific & Medical Conferences
12	Biobanks & Sample Collections

Foreword

Infection-associated chronic conditions (IACCs), including ME/CFS and long COVID, are some of the largest emerging health problems globally. In short, thanks in significant part to the COVID-19 pandemic, they have become hugely burdensome, cause immense suffering and disability, and are some of the most underfunded diseases relative to their burden in the high-income countries such as the UK.

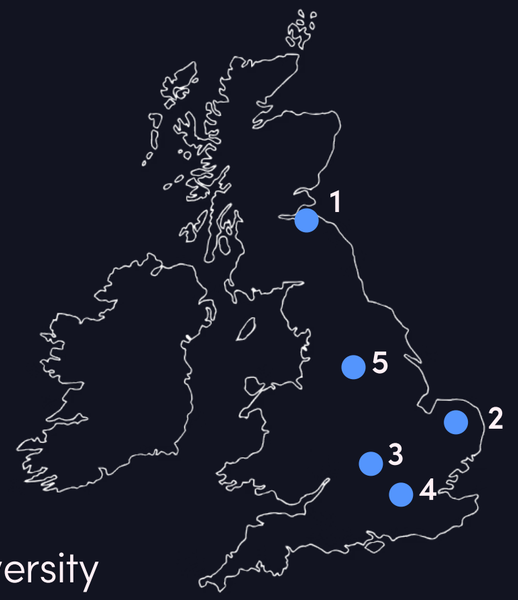
For example, in the UK, data from the ONS indicates close to 2m people are now living with long COVID, whilst the number with ME/CFS is likely around - or even exceeding - 1m, with huge associated economic cost.

However the UK, with its advanced life sciences industry & ever-growing tech clusters, has a major opportunity to lead the unravelling of these diseases, and to provide diagnostics, treatments and ultimately cures to a global population. In the same way that climate tech has become a major economic opportunity to solve a serious global problem, we believe an equivalent peril & promise applies to IACCs.

— Rory Preston, Founder of CrunchME

The UK hosts a number of research groups with significant focus on ME/CFS research, alongside emerging groups who have become more recently involved

1. Prof. Chris Ponting - Ponting Research Group - Institute of Genetics & Cancer, University of Edinburgh
2. Prof. Simon Carding - Carding Lab - Quadram Institute, Norwich
3. Dr Karl Morten - Morten Group - University of Oxford
4. Dr Luis Nacul - CureME - London School of Hygiene & Tropical Medicine
5. Dr Caroline Dalton - Advanced Wellbeing Research Center - Sheffield Hallam University



Other UK-based research groups with studies into ME/CFS

6. Prof. Michael Hughes - Center for Biomedical Engineering - University of Surrey | 7. Prof. Dmitry Veprintsev - Veprintsev Lab - University of Nottingham | 8. Physios for ME | 9. Prof. Ruth Jarrett - School of Infection and Immunity - University of Glasgow | 10. Prof. Douglas Kell - DBK Group - University of Liverpool

ME/CFS

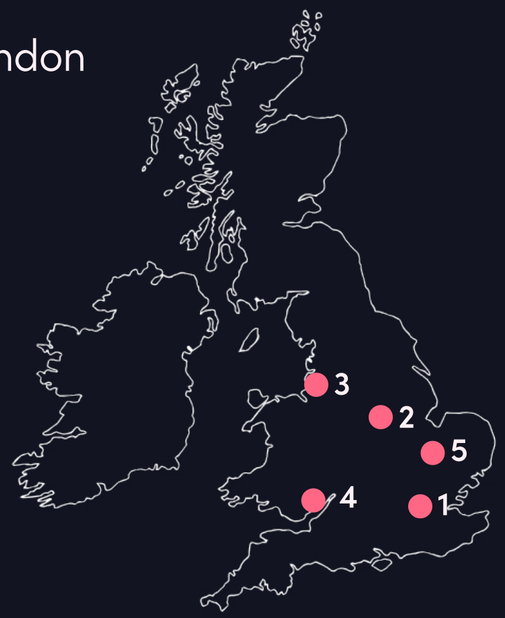
UK ME researchers are currently focused on the roles of genetic factors, the gut microbiome and blood factors like microclots, along with diagnostic biomarkers

Group Leader	Quick Research Summary
Prof. Chris Ponting	Leads the DecodeME study, the world's largest genetic investigation into ME. This research aims to identify genetic variations that may predispose individuals to ME/CFS, enhancing understanding of its causes and informing potential treatments.
Prof. Simon Carding	Investigating the role of gut microbiota and the immune system in ME/CFS. Their research includes studying the intestinal virome's impact on microbial dysbiosis and exploring microbiome-targeted interventions, such as the RESTORE-ME trial, which assesses the efficacy of Microbiota Replacement Therapy in ME/CFS patients.
Dr Karl Morten	Focusing on diagnostic biomarkers and underlying mechanisms. They have developed a blood test using Raman spectroscopy with 91% accuracy and are investigating mitochondrial dysfunction and gut microbiome imbalances to better understand the disease and identify potential treatments.
Dr Luis Nacul	Directs the UK ME/CFS Biobank (UKMEB), the first ME/CFS-specific biobank in Europe, and one of the first in the world. It has collected over 30,000 aliquots of blood from patients with ME/CFS and multiple sclerosis (as well as healthy controls), using a rigorous and consistent set of scientific protocols
Dr Caroline Dalton	Currently investigating the presence of microclots and other blood factors in ME/CFS patients, and their effects on cellular function and metabolism - potentially helping to explain post-exertional malaise (PEM). They are also aiming to identify diagnostic markers and understand the underlying biology of the disease.

ME/CFS

A number of UK research groups have become involved in long COVID research, especially those with prior expertise in immunology and infection

1. Prof. Danny Altmann - Dept. of Immunology & Inflammation - Imperial College London
2. Prof. Mark Faghy - Human Sciences Research Center - University of Derby
3. Prof. Douglas Kell - DBK Group - University of Liverpool
4. Prof. David Price - School of Medicine - University of Cardiff
5. Dr. Benjamin Krishna - Cambridge Institute of Immunology & Infectious Diseases - University of Cambridge



Other UK-based research groups with studies into Long COVID

6. Prof. Manoj Sivan - Faculty of Medicine & Health - University of Leeds | 7. Prof. Amitava Banerjee - Institute of Health Informatics - University College London | 8. Dr. Victoria Male - Dept of Metabolism, Digestion & Reproduction - Imperial College London

Long COVID

UK Long COVID researchers are currently focused on immune system dysfunction and resulting inflammation, along with viral persistence and metabolic disruption

Group Leader	Quick Research Summary
Prof. Danny Altmann	Focused on understanding the immunological mechanisms underpinning Long COVID, examining how persistent symptoms may arise from varied pathways such as autoimmune responses, viral persistence, and inflammation. Aims to stratify patients into distinct phenotypes for better diagnosis and development of targeted therapies.
Prof. Mark Faghy	Investigating the underlying mechanisms and patient impacts of Long COVID. His team is currently pioneering one of the UK's first clinical trials—testing remdesivir as a potential treatment (ERASE-LC)—to evaluate whether antiviral therapy can alleviate persistent Long Covid symptoms and improve quality of life.
Prof. Douglas Kell	Investigating the biochemical and immunological factors behind Long COVID. His work examines dysregulated metabolic pathways—including disruptions in iron metabolism—and investigates the role of microclots in perpetuating systemic inflammation, aiming to identify novel biomarkers and therapeutic targets.
Dr David Price	Investigating the role of immune system over-activation in Long COVID, and the resulting creation of inflammatory proteins circulating through the body. Looking to use this understanding to develop therapies.
Dr Benjamin Krishna	Investigating the molecular mechanisms behind Long Covid. His work investigates aberrant clot formation and immune dysregulation, focusing on inflammatory biomarkers. His work has found a distinct inflammatory signature in Long COVID patients, with elevated levels of IL-6 and TNF-a, which correlate with persistent symptoms.

Long COVID

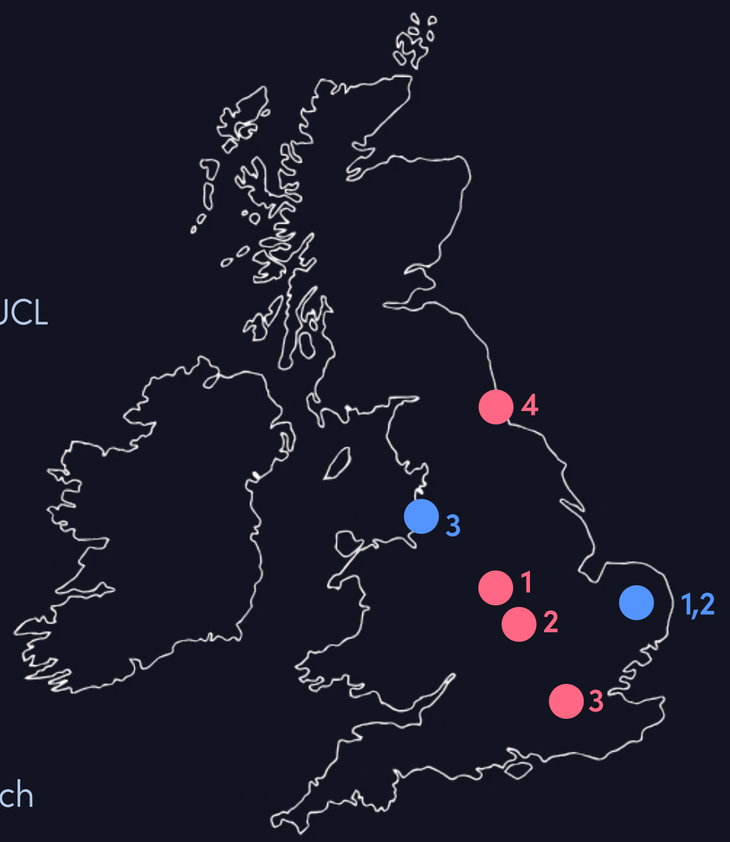
There are currently 7 clinical treatment trials in the UK, either in progress or upcoming, across Long COVID and ME/CFS

Long COVID

1. ERASE-LC | Remdesivir | Prof. Mark Faghy - University of Derby
2. PHOSP-I | Tocilizumab | Dr. Rachael Evans - University of Leicester
3. STIMULATE-ICP | i. Colchicine, ii. Famotidine + Loratadine, iii. Rivaroxaban | Prof. Amitava Banjeree - UCL
4. PAUSING-PCF | Vagus Nerve Stimulation (VNS) | Demetris Soteropoulos - University of Newcastle

ME/CFS

1. LIGHT ME UP | Photobiomodulation | Prof. Simon Carding - Quadram Institute, Norwich
2. RESTORE-ME | Faecal Microbiota Transplant (FMT) | Prof. Simon Carding - Quadram Institute, Norwich
3. VNS Pilot | Vagus Nerve Stimulation (VNS) | Karen Leslie - University of Liverpool, Physios for ME



UK clinical trials for Long COVID are targeting a number of different disease mechanisms, including viral persistence, inflammation, clotting and vagus nerve dysfunction

Trial Name	Quick Summary
ERASE-LC In Progress	This trial evaluates the feasibility of using the antiviral Remdesivir to treat Long COVID by targeting viral persistence. Participants will undergo assessments before and after a five-day course of the drug to measure its impact. If well tolerated, results will inform a larger trial on its effectiveness.
PHOSP-I In Progress	This trial investigates whether Tocilizumab, an anti-inflammatory drug already in use for severe COVID-19 cases, can improve symptoms such as fatigue, brain fog, breathlessness and pain, by reducing inflammation. This trial is placebo controlled and involves around 152 participants across 15 UK hospitals.
STIMULATE-ICP In Progress	This mutli-arm trial investigates the potential for several drugs targetting different mechanisms: Famotidine and Loratadine (antihistamines), Rivaroxaban (an anti-clotting drug), and Colchicine (an anti-inflammatory drug). Participants are randomly assigned to receive a drug or standard care.
PAUSING-PCF In Progress	This trial investigates whether non-invasive vagus nerve stimulation can reduce fatigue in Long COVID. This involves applying a mild electrical stimulation to the ear, with the study aiming to assess its impact on fatigue, brain activity, and inflammation. It will also help to asses if vagus nerve dysfunction plays a key role in fatigue.

Long COVID

UK clinical trials for ME/CFS, which are so far few in number, are targeting mitochondrial function, gut microbiota and vagus nerve dysfunction

Trial Name	Quick Summary
LIGHT ME UP In Progress	Investigating whether at-home red light therapy can improve mitochondrial function and reduce fatigue. By targeting mitochondrial dysfunction and compromised energy production, the study aims to assess changes in physical and cognitive function through activity monitoring, sleep tracking, and symptom questionnaires.
RESTORE ME In Progress	Investigating whether Faecal Microbiota Transplantation (FMT) can improve symptoms of ME. The study will transplant microbiota from healthy donors into participants with ME to assess its impact on fatigue, pain, and gut disorders. This is based on growing evidence that gut microbiota imbalances may contribute to ME symptoms.
taVNS Pilot In Progress	The taVNS for ME trial is a feasibility study investigating whether transcutaneous vagus nerve stimulation (taVNS) can improve symptoms of autonomic dysfunction in ME. By delivering non-invasive electrical stimulation to the ear, taVNS is thought to influence the autonomic nervous system, potentially alleviating symptoms such as fatigue.

ME/CFS

The UK has several tech and biotech companies focused specifically on ME/CFS and Long COVID, including wearables and sophisticated diagnostics

Visible

Visible combines a heart rate monitor with an app to help with pacing for energy-limiting conditions, including ME/CFS and Long Covid.

HQ: London

CEO: Harry Leeming

Latest Funding: Pre-Seed (£0.85m)

PrecisionLife

PrecisionLife has a combinatorial analytics & AI platform for developing personalised therapies for patients suffering from chronic diseases, including ME/CFS.

HQ: Oxford

CEO: Steve Gardner

Latest Funding: Series A (£2.38m)

Attomarker

Attomarker are creating new rapid diagnostic tools for biomarkers in diseases including Long Covid and ME/CFS.

HQ: Exeter

CEO: Andrew Shaw

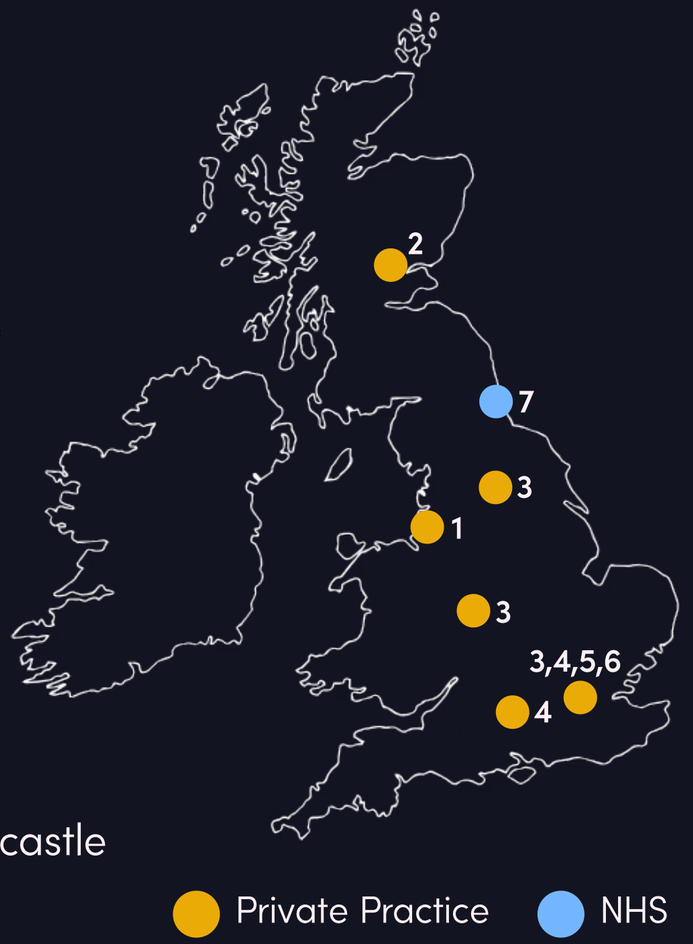
Latest Funding: Seed (£3m)

Other UK-based tech companies relevant to ME/CFS and/or Long Covid

Amatica Health - Blood testing examining biomarkers across multiple biological systems implicated in ME/CFS & Long COVID pathophysiology | Sano Genetics - Platform for clinical trial recruitment, genetic testing, and long-term patient engagement | Bearable - Symptom tracking app for chronic health conditions | Open-OH (Elaros) - Symptom tracking for Long Covid and ME/CFS | Co-EQ - Marketplace for accessing community voices for policy & healthcare research related to chronic illness

High quality care for both ME/CFS and Long Covid in the UK is predominantly available through a small number of specialist private practices

1. Dr Binita Kane - Howell Medical Long Covid Clinic - Liverpool
2. Dr Claire Taylor - Long Covid Clinic - Perth
3. Dr Ben Sinclair - Dr Finlays Private Practice - Birmingham, London, Leeds
4. Dr Tina Peers - Private Practice - Farnham & Horley (Surrey), London
5. Dr Paul Glynne - The Physician Clinic - London
6. Dr William Weir - Private Practice - London
7. Dr Rae Duncan - The Newcastle upon Tyne NHS Foundation Trust - Newcastle



The UK hosts several notable scientific & medical conferences on ME/CFS & Long COVID

LC

Clinical Post-COVID Society Conference

This conference is organised by a working group of the British Society of Physical and Rehabilitation Medicine (BSPRM), which is led by Prof Manoj Sivan - a Long COVID researcher at Leeds.

Date: 26th March 2025

Location: Birmingham

Attendance: In Person

ME LC

MitOX 2025 Conference

This conference, organised by Nuffield Department of Women's & Reproductive Health at Oxford University, focuses on mitochondrial research and includes talks on mitochondrial aspects of Long COVID and ME/CFS research.

Date: 3rd April 2025

Location: Oxford

Attendance: In Person & Virtual

ME

Invest in ME International Conference

Organised by the UK charity Invest in ME Research, this is a long running annual conference (2025 will mark the 17th edition) bringing together some of the world's foremost ME researchers.

Date: 30th May 2025

Location: Cambridge

Attendance: In Person & Recorded

Biobanks and sample collections 🩸

	The UK ME/CFS Biobank	UK Biobank	DecodeME
Overview	Specialist ME/CFS biobank, administered by the CureME team at the London School of Hygiene & Tropical Medicine (LSHTM), with samples stored at the UCL/RFH BioBank facility in London.	Large non-specialist (general population cohort) biobank, organised as an independent entity and supported by the MRC, The Wellcome Trust, UK Government and private donors.	Large genetic biobank focused on ME/CFS, based on the DecodeME study, run by the MRC Human Genetics Unit at the University of Edinburgh, in collaboration with Action for ME.
Samples	Contains > 30,000 blood sample aliquots from > 600 participants, including individuals diagnosed with ME/CFS (mild, moderate and severe), multiple sclerosis (MS), and healthy controls. Participants diagnosed by clinicians.	Contains biological samples & health-related data from 500,000 UK participants, inc. some with ME/CFS based on self-reported medical history, health records & clinical diagnosis codes. Typically used as control data for ME.	Contains questionnaire data (phenotype and clinical information) from c. 25,000 participants, with c. 20,000 of these invited to provide saliva samples for DNA testing. Includes a COVID-triggered ME/CFS cohort.
Access	Samples and/or data are accessible to researchers globally aiming to advance clinical research into ME/CFS, in line with UKMEB's mission. Applications made online.	Any researcher (academic, commercial, or non-profit) can apply to use UK Biobank data and samples for health-related research that is in the public interest. Applications made online.	Researchers can apply to access data and samples from DecodeME, which will be reviewed and decided on by the DecodeME Data Access Committee.

This report is an active work in progress

If you have feedback or suggested alterations and additions, you can email rory@crunchme.org

---

Declarations of Interest

Rory Preston is a shareholder in Visible Health, and has previously held a paid position there as Data Science Lead