

Windsor research events for publics comms



About the event

On 3–4 March, Action for ME hosted a research event at Windsor Castle, bringing together 27 international experts from different sectors. The event was made possible by a private donor and held in partnership with St George's House, Windsor – a place known for bringing people together to explore important societal issues. Our CEO, Sonya, is a fellow of the House.

Purpose and focus of the event

Opportunities for collaboration in ME research remain very limited. This meeting created a rare space for open discussion at a key moment: DecodeME is nearing completion and Long Covid research is growing. Yet people with ME and their close ones are still waiting for real progress. Urgent action is needed to respond to the growing number of people affected.

We tried to include diverse set up participants: researchers working in ME and Long Covid joined professionals from other fields – many of whom were new to this area. Half of those attending had personal experience of ME or Long Covid (for example, they had a family member who was affected or had their own lived experience). This diversity helped generate new ideas and partnerships.

Discussions focused on genetics, diagnosis, and developing treatments – reflecting our work in the Genetics Centre of Excellence and new findings from the [DecodeME](#) and [LOCOME](#) studies. Several participants presented other work in this area.

While biological understanding of ME is still limited, planning for the future is essential. This includes preparing for the delivery of potential treatments, as identified by the [ME Priority Setting Partnership](#). Attendees explored lessons from other conditions such as MND and ALS, and discussed what helps or blocks access to treatments in health systems like the NHS. They also discussed the importance of including other post-infectious and overlapping illnesses. The event was also a chance to reflect on how to make a stronger case for ME and Long Covid research – to funders, policymakers, the commercial sector, philanthropy and the media.

What will happen next?

The group was kept small to support dialogue and shared ownership of next steps. New partnerships were formed, including plans to advance [SequenceME and long COVID](#)

We are currently in discussion with several philanthropic organisations who have expressed a clear interest in collaborating and funding part of the SequenceME project.

We also arranged one-to-one follow-up conversations with all participants to support continued progress. There was also clear interest in building ongoing group collaboration, while staying open to others who were not in the room. Any next steps will be designed to build on and complement existing global efforts.

The Windsor event therefore marks the beginning of a longer journey. While we do not expect immediate impact, we have created new connections, formed partnerships, and built a shared commitment to improve the quality and impact of research for ME and Long Covid.

We will share updates about future group meetings and confirm new partnerships as they happen. If you have any questions, please get in touch..

Full list of attendees:

- **Prof. Daniel Altmann**, Professor of Immunology, Hammersmith Hospital Campus, Imperial College London
- **Oved Amitay**, Advisor, Solve ME/CFS Initiative
- **Lord James Bethell**, Member of the House of Lords
- **Ms Sonya Chowdhury**, Chief Executive Officer, Action for ME
- **Dr Mick Cooper**, Market Analyst, Office for Life Sciences
- **Dr Brian Dickie**, Chief Scientist, MND Association
- **Mrs Olivia Elliot**, Advisor, Action for ME
- **Mrs Rowan Gardner**, Co-founder and Chief Business and Investment Officer, PrecisionLife
- **Dr Steve Gardner**, Chief Executive Officer, PrecisionLife
- **Kate Gerrand**, Senior Research Liaison Manager for Health Protection, Department of Health and Social Care
- **Mr Kyle Hatchard**, STFC Hartree Research Institutes
- **Prof. Sir Stephen Holgate**, MRC Clinical Professor, University of Southampton
- **Ms Daphne Lamirel**, Research Manager, Action for ME
- **Prof. Nick Lemoine**, Director of Strategic Development Coordinating Centre NIHR Research Delivery Network
- **Mrs Tonya McSherry**, VP Commercial EMEA, Oxford Nanopore Technologies
- **Prof. Dr Alain Moreau**, Université de Montréal/CHU Sainte-Justine and Director, ICanCME Research Network on Myalgic Encephalomyelitis
- **Mr Sean O'Neill**, journalist, The Times
- **Prof. Chris Ponting**, Chair of Medical Bioinformatics and Principal Investigator at MRC Human Genetics Unit, University of Edinburgh
- **Dr John Redd**, CEO, Schmidt Initiative for Long Covid (SILC)
- **Ms Amy Rochlin**, Executive Director, Metrodora Foundation
- **Dr Audrey Ryback**, Research Fellow, Clare Francis
- **Dr Nirmala Santiapillai**, VP, Global Services, Oxford Nanopore Technologies
- **Prof. Sir Terence Stephenson**, Clinical Academic Paediatrician
- **Prof. David Strain**, Professor, University of Exeter Medical School
- **Prof. Dmitry Veprintsev**, Professor of Molecular and Cellular Pharmacology, University of Nottingham
- **Prof. Jennifer Visser-Rogers**, Chief Scientific Officer, Coronado Research
- **Dr Matthias Wielscher**, Genetic Epidemiologist, Medical University of Vienna