



All-Party Parliamentary Group for Myalgic Encephalomyelitis
Minutes of the Inaugural Meeting, 5 March 2025 at 17.00,
Committee Room 12, Westminster Palace

NOTE: THESE MINUTES ARE DRAFT UNTIL APPROVED BY MEMBERS AT THE NEXT APPG MEETING

Present

Secretariat

Sonya Chowdhury (SC)/Chris Khadem (CK) & Mike Mitchell (MM)

Parliamentarians

Jo Platt MP (JP); Paul Waugh MP (PW); Baroness Thornton (BT); Munira Wilson MP (MW); Alison Gardner MP (AG); Debbie Anderson MP (DA); Lord Offord (LO)

In attendance

Lee McGill (LM) & Mark Joannides (MJ) – DHSC; for items 1 and 2 only

Apologies

Number of apologies due to meeting clashes.

1. Minutes & Matters Arising

DECISION: The minutes of the meeting were approved as an accurate record. All matters arising are covered on the agenda or complete.

2. Delivery Plan on ME

MJ outlined that the purpose of today's DHSC attendance is to identify and agree how APPG members can engage and influence the delivery plan and provide clarification on next steps. From a broad context, need to consider the NHS 10 Year Health Plan. Currently, DHSC is developing this and there is a real ambition to be radical in thinking about population health; ME has to be part of the consideration and many stakeholders

have inputted. It's still in development. This is a period of change with new government including new minister and a new interim CEO of NHS England.

There is also the forthcoming spending review which will determine budgets from 2026-27 onwards and discussions about what this looks like are happening currently. The financial context is very well known. The approach is about how to be creative and how to use what's already in place and how to prioritise ME within this.

LM outlined that taking a backwards look, the delivery plan's focus in 2022 was only on ME/CFS but very mindful of the impact since of Covid and Long COVID. The Consultation summary report took longer than planned to produce due to the level of responses which was high and the large number of qualitative questions that needed analysing. The 25-page report was published in December, at which point then lead Minister, Andrew Gwynne, signalled his ambition to deliver the final delivery plan by end of March.

He stated there has been a strong focus on engagement with stakeholders and the Task and Finish Group was stood back up with additional members. While the APPG wasn't invited to its membership itself, SC is a member and has clearly fed back and kept members updated. The interim delivery plan was, however, developed with the earlier APPG report as a foundation.

The three meetings of the Task and Finish Group since January have been incredibly powerful, and the focus now needs to be on the final delivery plan's actions rather than the detail of the background information/context. There has been no new funding secured to support the delivery plan yet from previous spending reviews.

DHSC is hearing loud and clear that the plan doesn't go far enough on research, as well as in some other important areas. It is very clear that there is more to do in the research space and that not enough high-quality research has been funded to date. DecodeME has been an obvious exception to this. Funders and applicants give very different perspectives, but the situation needs to change. There is no ring-fenced funding for ME/CFS research and there are no plans to change that. DHSC is awaiting for a meeting with MRC and others to discuss how to break this cycle.

NHS England (NHSE) has devolved commissioning of ME/CFS services to local ICBs and consistency in ME services and support is an issue, including with recognition of ME and follow-up care and support. NHSE is represented on the Task and Finish Group. There has been an NHSE-led stocktake which, as expected, identified variation in provision of services throughout England and that more needs to be done to reduce that variation. There is a focus on broader engagement across government departments, especially DWP and DfE, too, given that those departments own some of the delivery plan's actions.

Following the three Task and Finish Group meetings over the last 6 weeks, it is clear that there is much more to do on developing tangible and impactful actions and there is also a need to fully engage the new lead Minister, Ashley Dalton on the work to date and her preferences on next steps, including the publication timetable. The plan's draft actions will be shared with the APPG in the coming weeks and, later, a draft of the final delivery plan too.

The discussion was then opened up to APPG members.

It was noted that there are discussions about collaborative working with the APPG on Long Covid. JP has also engaged with the new Minister. It was also noted the lack of government-funded research in comparison to other countries.

The economic position of around £23.5bn cost to the economy of ME and ME-like symptoms was highlighted.

There was recognition of the experience of people with severe and very severe ME, including that highlighted through the Coroner's Inquest following Maeve Boothby-O'Neill's death. LM highlighted that DHSC had provided a response to the Coroner within the statutory deadline.

It was highlighted that there is a clear lack of funding and priority given to ME and this needs to be addressed alongside the updated data that exists re: prevalence, cost to the economy etc.

MJ highlighted that the Delivery Plan, when published, is not the end of the journey and more must be done beyond this alongside ongoing monitoring and evaluation of impact.

It was noted that there are gender inequalities given the higher proportion of women affected and this requires focus too.

Action for ME's Parliamentary Champions have been asking a series of questions; acknowledged it is important for parliamentarians, more broadly, to be aware of the impact of ME.

3. APPG workplan and priorities

The Officers met recently and will continue to do so to ensure delivery and monitor progress.

Members approved the proposed workplan and communications strategy considering additional proposals that had been submitted since the last meeting from charities and members of the community.

The communications strategy recognises the importance of using the APPG to raise the visibility of ME, act as the voice of the community in Parliament and communicate regularly with those with ME.

The plan for this year will need to be further developed but agreement was given to the following:

- **Additional Meeting TBC** for consultation on Delivery Plan on ME
- **Wednesday 14th May** | Second meeting of 2025 (first with Long Covid APPG)
- Topics: Research; launch of Severe ME Inquiry
- **TBC (Sept/Oct)** | Third meeting of 2025
- Topics: Review inquiry evidence and recommendations/next steps; update on Delivery plan implementation; preparing for a Parliamentary drop-in on ME, Long Covid and overlapping illnesses
- **TBC (Nov/Dec?)** | Fourth meeting of 2025 (second with Long Covid APPG)
- Topics: to be agreed dependent on Delivery Plan actions/Inquiry output

Agreed Actions

Dates TBD

Action	Who
Write to Gail Allsop on behalf of APPG to explore what's happening from DWP perspective	JP
Parliamentary questions for members to be circulated	SC
Confirm timescales and process for APPG engagement/consultation on final delivery plan actions	LM
Terms of reference and associated paperwork to be shared with members for the severe ME inquiry	SC
Nominations to be made for severe ME inquiry panel to SC/JP	All