

INFORMATION FOR STAKEHOLDERS

Development of a Delivery Plan on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

17th August 2022

The purpose of this publication is to provide information about work underway to develop a Delivery Plan on ME/CFS.

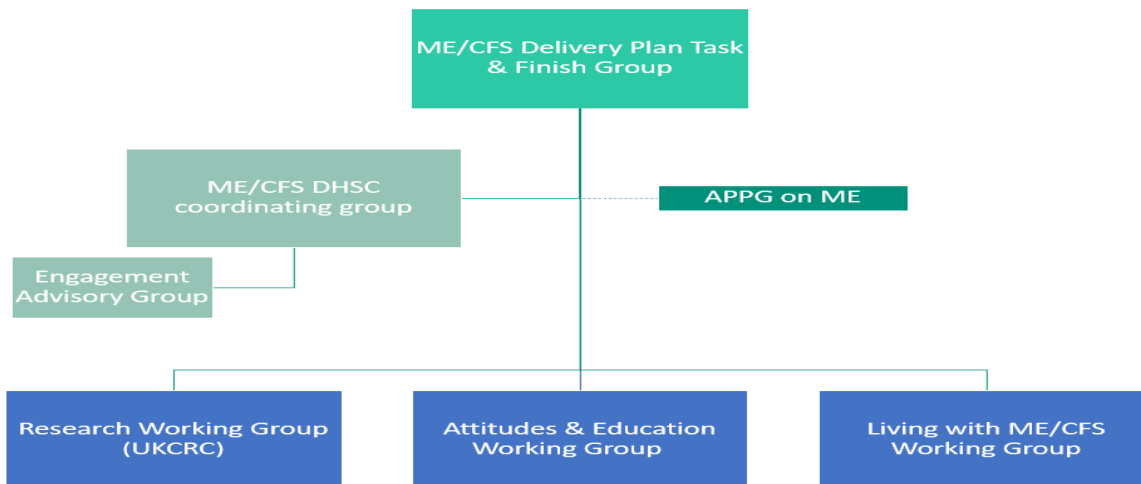
Introduction

On the 12 May, World ME Day, the former Secretary of State for Health and Social Care (Sajid Javid) announced the Government's intention to develop a cross-Government Delivery Plan on ME/CFS for England. This intention was published in a Written Ministerial Statement laid in Parliament (<https://questions-statements.parliament.uk/written-statements/detail/2022-05-12/hcws23>).

Development of the plan will build on the recently published 'Rethinking ME' report by the All-Party Parliamentary Group on ME /CFS, (Publications - All-Party Parliamentary Group on ME (appgme.co.uk)), the recently updated guidance from the National Institute for Health and Care Excellence (NICE) (<http://www.nice.org.uk/guidance/ng206>), and the recently announced top ten (plus) research priorities for ME/CFS (The full report - ME/CFS Priority Setting Partnership (psp-me.co.uk)).

Governance structure

A set of working groups has been established to support development of a delivery plan.



APPG : All-Party Parliamentary Group on ME

The purpose of the Working Groups is set out below.

- **The Delivery Plan Task & Finish Group** oversees and monitors the progress of all the other groups to develop the delivery plan. Its job is to make sure that the groups work effectively together, to avoid duplication or resolve conflicts.
- **The All-Party Parliamentary Group on ME** consists of MPs and Peers and so is not directly connected into the Delivery Plan governance structure. It is shown with a dotted line on the diagram, to indicate that we will connect with the APPG on ME to keep the group updated and welcome any views or further information from its ongoing work. *All-Party Parliamentary Group on ME (appgme.co.uk)*
- **The DHSC Co-ordinating Group** co-ordinates all stages of the delivery plan development.
- **The Engagement Advisory Group** advises on options for engagement, to ensure that anyone who wants to is able to share their experiences of living with ME/CFS and working in services to support people with ME/CFS, to shape the Delivery Plan.
- **The Research Working Group** is responsible for looking at all aspects involved with research into ME/CFS, including funding, applications and the challenges and problems that exist for research into ME/CFS. They will also propose actions to address these and find ways forward for research in future.
- **The Attitudes and Education Working Group** is responsible for looking at the current problems and developing specific solutions to address the challenges surrounding attitudes towards ME/CFS, including by those involved in the care of people with ME/CFS and the education of healthcare professionals about ME/CFS.

- **The Living with ME/CFS Working Group** is responsible for looking at quality of life and the broad range of services including health and social care, education and training and the welfare system. Other aspects being considered include loneliness/social isolation, carers and support for people in/into paid and unpaid work.

Membership of the Groups

Chairs

- There are two co-chairs on each Working Group and the Engagement Advisory Group.
- One co-chair has been invited to represent people with lived experience of ME/CFS. These nominations have been made by Action for ME, as this organisation has previously been involved in recruiting people with lived experience to join national research projects into ME/CFS. All co-chairs invited to represent people with lived experience of ME/CFS have previously been recruited through one of these processes.
- The other co-chair has been invited into the role by the government because of their professional status and relevant expertise.
- The Delivery Plan Task and Finish Group is chaired by a Director from the Department of Health and Social Care.

People with lived experience of ME/CFS

- There are two places for people with lived experience of ME/CFS (which includes carers) on each of the Attitudes and Education and Living with ME/CFS Working Groups and the Engagement Advisory Group.
- These people have been nominated by Action for ME and BACME (British Association of Clinicians in ME) because they have already been through a national recruitment process to represent the ME/CFS community.
- The Patient Advisory Group as a whole group has a place on the Attitudes and Education Working Group and the Research Working Group. Different members rotate into this place depending on availability and capacity whilst another member supports by taking notes.
- There are also places on the Research Working Group for other people with lived experience, including carers.

ME/CFS charities and organisations

- There are three places for people nominated by Forward ME on each of the Attitudes and Education and Living with ME/CFS Working Groups and the Engagement Advisory Group. Forward ME is the recognised umbrella organisation for many ME/CFS charities and organisations.

Additional members

- Other members of the Attitudes and Education and Living with ME/CFS Working Groups have been invited to join for different reasons. Some have specialist expertise because they work in ME/CFS services. Others represent organisations such as professional bodies (e.g. Royal Colleges), the NHS (e.g. NHS England, commissioners of services), or Social Care. Some members are responsible for education and training (e.g. DHSC, General Medical Council, Health Education England). Others work in the relevant Government Departments for wider public services (e.g. Department for Education, Department for Work and Pensions) or Arms-Length Bodies (e.g. the National Institute for Health and Care Excellence).
- Other members of the Research Working Group represent organisations such as funders (e.g., the National Institute for Health and Care Research, Medical Research Council, ME Research UK), researchers and clinicians. Forward ME represents ME/CFS charities and organisations who don't commission research.
- The members of the Delivery Plan Task & Finish group include all the co-chairs of the working groups, ME/CFS specialists, senior DHSC and cross government departmental officials, representatives from NICE, NHS England and three ME/CFS charity/organisation representatives nominated by Forward ME. The Scottish, Welsh and Northern Ireland Governments are also represented.
- The DHSC Coordinating Group consists of DHSC officials.
- Further detail about Working Group membership will be published once necessary consent for information sharing has been gathered.

Timescales for the work

- The Working Groups have been meeting regularly from June 2022 to discuss current problems, a vision for the future and proposals for action. These will be developed into a draft Delivery Plan.
- We intend to release the draft Delivery Plan later this year to support wider engagement on the plan and proposals for action.
- Everyone will have an opportunity to share their experience and give their views on the draft Delivery Plan at this point.
- All the evidence will be taken into account before the final Delivery Plan is published next year.