

INFORMATION FOR STAKEHOLDERS

Work underway to support the development of a Delivery Plan on Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS)

20th September 2022

Introduction

The purpose of this publication is to provide a summary of the meetings held to date to develop proposed content for a draft cross-government Delivery Plan on ME/CFS.

Working groups have been established to do this work. An explanation of these groups was published by the Department of Health and Social Care (DHSC) on 17 August 2022 and shared with all working group members for wider distribution. Many organisations have published this information on their websites – for example :

[DHSC proposal on the Delivery Plan on M.E./CFS | Action for ME](#)

[The DHSC have released details of their process in the Development of a Delivery Plan on ME - #MEAction Network](#)

[Development of a Delivery Plan on Myalgic Encephalomyelitis / Chronic Fatigue Syndrome \(ME/CFS\) | The ME Association](#)

[DHSC TASK GROUP UPDATES | Forward ME \(forward-me.co.uk\)](#)

Delivery Plan Task and Finish Group

This oversight group has met three times since June 22. Terms of Reference have been approved for this group and the other working groups, to ensure that all members are clear about the purpose of meeting and the scope of their responsibilities. Members have heard about progress being made by each of the three working groups since June. Risks and issues for the Delivery Plan have been discussed with mitigating actions agreed in response. Members have had the chance to ask questions to ensure understanding, as well as challenge and offer suggestions.

Research Working Group

This group met first to discuss ways of working and the Terms of Reference which sets out the aims of the group, and how to deliver on these aims. Their work will build on the discussions that took place at the Research Roundtable held 8 June 2022, chaired by the former Secretary of State for Health and Social Care, and the top ten plus research priorities from the James Lind Alliance Priority Setting Partnership on ME/CFS. At the second meeting on 1 September, it was agreed that the work would be taken forward in 3 separate sub-groups, focusing on :

1. Research Strategy
2. Building capacity and capability
3. Raising awareness and building trust

Attitudes and Education Working Group

This group met first to discuss Terms of Reference and an initial set of the problems to be addressed, in relation to professional attitudes towards ME/CFS and professional education about ME/CFS.

Feedback from group members has been submitted to DHSC about these problems, their causes and effects on children and adults with ME/CFS (including people with severe and very severe symptoms), their carers and professionals. As a result, the set of problems were refined.

Further feedback has recently been submitted on the desired impacts to be achieved by this work and possible actions that will help achieve this impact. These impact statements and suggested actions were discussed at the meeting held 8 September 2022. A draft list of actions has been developed which need further exploration.

Living with ME/CFS Working Group

This group has met twice. At the first meeting, we discussed Terms of Reference and the set of problems to be addressed with regard to the provision of services to support children and adults with ME/CFS (including people with severe and very severe symptoms) and quality of life.

Following feedback from group members, causes of the problems and their effects were discussed at the second meeting.

Topic-based workshops are taking place in September and October to gather views on the desired impact to be achieved and possible actions to address the agreed set of problems and deliver this impact. The topics for the workshops are – 1) Adult Social Care, 2) Quality of Life, 3) Welfare, Employment, Adult Training and Education, 4) Health Services and 5) Children and Young People. Relevant experts, including additional people with lived experience, are being invited to attend these workshops.

Engagement Advisory Group

This Group will first meet in September.