Australian Government
National Health and Medical Research Council

BUILDING
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AUSTRALIA

Administrative Report

The Myalgic Encephalomyelitis/Chronic Fatigue Syndrome
Advisory Committee Report to the NHMRC Chief Executive Officer

30 April 2019

NHMRC

This administrative report refers to the development of *the Myalgic Encephalomyelitis / Chronic Fatigue Syndrome Advisory Committee Report to the NHMRC Chief Executive Officer.*

Background

In recognition of the concerns of the Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) sector about the need for increased ME/CFS research, greater community awareness and up to date clinical guidance, the Office of the National Health and Medical Research Council (ONHMRC) established the ME/CFS Advisory Committee (the Committee) in October 2017. The purpose of the Committee was to advise the NHMRC Chief Executive Officer (CEO) on the ME/CFS research and clinical guidance needs in Australia. To do so, the Committee prepared the *Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Advisory Committee Report to the NHMRC Chief Executive Office* (the ME/CFS Report).

Contributors

ME/CFS Advisory Committee

The Committee was established under section 39 of the *National Health and Medical Research Council Act 1992* (the NHMRC Act). The ONHMRC consulted with medical colleges, research organisations and advocacy groups (Emerge Australia and ME/CFS Australia) to seek nominations for committee membership. The Committee included representation from researchers, clinicians and consumers from the ME/CFS sector.

Terms of Reference

The Committee will advise the NHMRC CEO on the research and clinical guidance requirements for Australia of ME and CFS.

To provide this function, the Committee will advise on:

1. the status of national and international research into ME and CFS
2. gaps in research on ME and CFS - this will include but not be limited to research on the immunology, psychology, microbiology and virology of the conditions, as well as any health services research
3. the status of clinical guidance on ME and CFS available to doctors and health professionals
4. requirements and opportunities for improved clinical guidance
5. any other issue on ME and CFS that the NHMRC CEO may request advice
6. submissions received through the public consultation process.

Membership

Members were originally appointed from 15 October 2017 to 31 November 2018 and appointments were subsequently extended to 30 April 2019 to allow for public consultation on the draft report.

The members were:

Professor Kwun Fong (Chair) - Thoracic and Sleep Physician at the Prince Charles Hospital and Professor at the School of Medicine, University of Queensland

Dr Gary Deed - Medical Practitioner, member of the Royal Australian College of General Practitioners (RACGP)

Professor Rachel Ankeny - Professor, School of Humanities, University of Adelaide

Associate Professor Suzanne Broadbent - Exercise Scientist and Physiologist, University of the Sunshine Coast

Professor Andrew Lloyd - Infectious Disease Physician, Principal Investigator at University of New South Wales, UNSW Fatigue Clinic

Professor Sonya Marshall-Gradisnik - Co-Director, National Centre for Neuroimmunology and Emerging Diseases (NCNED), Griffith University

Dr Kathy Rowe - Senior Consultant Physician at the Royal Children's Hospital Melbourne, Department of Paediatrics, University of Melbourne

Ms Simone Eyssens - Consumer Representative, Psychologist (non-practising) , ME/CFS Consumer advocate

Ms Sally Missing - Former President of Emerge Australia, committee support person for Ms Simone Eyssens

Ms Penelope McMillan - Consumer Representative, President of ME/CFS Australia (SA).

Declarations of Interest Process

Appointees of NHMRC committees are required to disclose any interests in accordance with section 42(A) of the NHMRC Act and section 29 of the *Public Governance, Performance and Accountability Act 2013*.

Members of NHMRC committees provide high quality, expert and independent advice that allows NHMRC to fulfil its functions under the NHMRC Act. Members are appointed to allow NHMRC to seek advice from consumers and the best health care and research professionals across Australia, offering the highest standard of information. Appointments are also made with consideration of balancing the benefit of having persons with expertise against the risks of their interests biasing the process.

Prior to the Committee's appointment, prospective members were required to disclose their interests in writing to ONHMRC and to identify, to the best of their ability, interests including:

- Relevant financial interests or relationships (e.g. employment, ownership, board membership, honoraria, consultancies, companies, organisations, individuals or research grants associated with ME/CFS).
- Relevant professional or organisational experience (e.g. publications, speeches, expert testimony).
- Other relationships or activities.

The NHMRC Executive reviewed nominated Committee members' disclosures of interest (DoIs) and determined no conflicts of interests that would preclude committee appointments.

Throughout the project and at each meeting, members of the Committee were reminded of their obligation to disclose any real, perceived or potential conflicts between their responsibilities for NHMRC and their personal interests or other professional responsibilities. All disclosures were recorded in the minutes of the Committee's meetings. A summary of disclosed interests of members was available on the NHMRC website throughout the duration of the project.

There were no instances during the project where it was determined that a disclosed interest warranted a member being absent from a discussion or decision.

NHMRC Project Team

A small project team from the Public Health Team in the Research Translation Branch provided project and secretariat support to the Committee.

Committee Meetings

All committee meetings were via videoconference and were no longer than two hours in length to support the attendance of the consumer representatives. In December 2017, the Committee met via videoconference to discuss the aims and to scope the project. In 2018 the Committee met six times via videoconference to progress the project.

In consideration of the complexity of the condition and the interest of the ME/CFS sector in the Committee's recommendations, the Committee recommended releasing the draft report for public consultation to inform the final report. In October 2018, the Committee met for the seventh time via videoconference to finalise the draft report and to confirm the public consultation questions. During March 2019, the Committee met via videoconference for the eighth and final time to consider public consultation comments, and to advise on finalising the Report.

Activities undertaken to inform the Committee's recommendations

Scoping Exercise

The Committee undertook a scoping exercise to gather information about current ME/CFS research initiatives nationally and internationally and to determine the status of clinical guidance. The Committee and the project team mapped the existing literature to identify gaps and themes in ME/CFS research, and clinical guidance.

Consultation

Consultation was undertaken both locally and internationally to inform the Committee's recommendations. The project team on behalf of the Committee consulted with relevant government agencies to gather information on policy needs, data collection and the status of clinical guidance for ME/CFS. This included the Department of Health, the Australian Institute of Health and Welfare and the Australian Bureau of Statistics. The Royal Australian College of General Practitioners and David Tovey, the Editor in Chief of the international Cochrane Library, were also consulted.

The project team consulted with major advocacy organisations including Emerge Australia and ME/CFS Australia (SA) as well as independent advocates on consumer needs and concerns.

The project team consulted with key Australian researchers including those at the Bio21 Molecular Science and Biotechnology Institute and the National Centre for Neuroimmunology and Emerging Diseases.

Relevant international agencies were approached to determine research gaps, to gather information on the status of clinical guidance and to seek collaboration opportunities. Teleconferences were held with the US National Institutes of Health, the UK National Institute of Health and Care Excellence, and the Canadian Institutes of Health Research.

Public Consultation

The draft ME/CFS Report was released for a 60-day public consultation from 21 December 2018 to 18 February 2019. The public consultation process was promoted through a media release and information published on the NHMRC website and NHMRC newsletter. In addition, more than 200 key stakeholders both nationally and internationally were emailed a public consultation notice. Over 250 completed public consultation submissions were received and respondents who agreed to have their submission published (in full or redacted as necessary) will be published on the NHMRC Public Consultation Portal.

Governance

In response to its Terms of Reference, the Committee guided the development of the ME/CFS Report and considered the public consultation comments in finalising their report.

Throughout the project, the Committee provided advice to the project team via the videoconferences and throughout the process as required. The public consultation draft of the report was tabled at the 216th session of Council and the final report was provided to the NHMRC CEO at the beginning of May 2019 for her consideration.

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